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In Over Their Heads

An Independent Report
on the condition of
**Provincial Home
Support Programs**

Based on the
Deloitte.
Review/5-year Plan
for the
Department of Health
& Community Services
from July 12, 2016

**Deloitte
Review
in 4 pages
on Page 39**

of the



GOVERNMENT OF
NEWFOUNDLAND
LABRADOR

by
**Barry Moores
Shoal Hr.**

Introduction

My name is Barry. I've written this report about the condition of our province's home support programming and made recommendations for action items to improve the system and intelligently utilize valuable resources.

This report starts with an analysis of the 2016 Deloitte Review of home support program delivery, the predecessor document to the Health Accord NL reports. The Deloitte document was commissioned by the province of Newfoundland and Labrador to define a five-year plan for how government will provide services for the poorest and most vulnerable people here. The report cost taxpayers a quarter million dollars.

Government and the regional health authorities claim they have achieved their goals in this process. This assertion from the individual responsible is contained in a letter to me included in the appendix to this document. Like the correspondents of old, I shall leave it to the readers to draw their own conclusions.

This document gives my family a record of my living conditions and attempts I made insisting for common sense improvements to the system. It also serves to compensate for a lack of institutional memory that contributes to the development of ineffectual, time and resource-wasting projects that do little to help the most vulnerable, but continue to be led by the same government structure and often by the same individuals. Doing the same thing over and over again and expecting a different result is commonly referred to in modern culture as a definition of insanity.

As for me, I've dealt with serious multiple sclerosis for 28 years. I can neither walk or stand. I have barely any use of my arms, hands or fingers. All computer tasks are done with the knuckle of my pinky and voice recognition. I suffer from a swarm of neuropathic discomforts. My small pension is well below the poverty line. 24-hr homecare is essential for me to function in any way.

Fortunately, my cognitive ability and acuity have continued to improve. I have 35 years work experience inside and outside the media. There's a cross-section of work, including my CV, at <http://behance.net/BGM>.



I have extensive background developing large projects, from research papers, as newspaper editor, 12 entries in the NL Encyclopedia, business/marketing plans, tourism guides, CNA's first distributed learning website and a collection of stories about life with longterm disability. (<https://artesian-paradise.tumblr.com/post/154682569900/true-stories-of-a-stationary-hobo-the-theory-of>)

It took more than four years to assemble this report. I have tried to make the analysis readable as possible. The point-by-point section breaks the Deloitte Report into four pages so it's easier to understand the recommendations. By their nature documents concerning government policy tend to be particularly dry reading. My report maintains some traditional structure, but has the critical distinction of including observations from the world. It tells a story and has sense of humour.

Please take the time to read my report. I've put my all into it. The failures in the system have a direct, negative impact on my life and more importantly, the lives of those who have no way to make their reactions known.

Barry Moores
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Overview

This review analyzes the realities of Newfoundland and Labrador's provincial home support programming since the release of the Deloitte Report on Health and Community Services in 2016, which claims to make a five year plan for the programs.

It has taken its author four years to compile and complete this document, as the person lives in Newfoundland with a severe disability on low income, a so-called "client" of these support programs.

The document examines the policy's expectation of success in the province's current regional health authority (RHA) environment and will provide as many details as possible to explain the obstacles that challenge the implementation process: confusion, poor communications, lack of skills and co-ordination across multiple levels of government, regional health authorities and the personal care industry. Bureaucratic silos, institutionalized self-entitlement issues amongst RHA and home care agency management and employees, including lack of skills, knowledge, judgment and overall common sense.

In the homecare agency and long-term care home environment, these problems are exacerbated by greed and absentee agency ownership, which wreaks havoc among the most vulnerable in the province and adversely affects countless individuals, households and families.

The report's author has observed and noted multiple instances where *homecare agency management has openly broken rules it has signed legal contracts to follow, most notably the Home Support Program Operational Standards*, which have consistently been ignored throughout the most recent decade of his being in the system.

Regional health authority management is observed as being unsuited to meet the mandate for which it was created: it should be noted it was created against public wishes.

Adoption of the Individualized Funding (IF) model is supposedly underway. This review also outlines the current system and presents conclusions about the problems and pitfalls of IF.

It also makes suggestions as to policy and initiatives.

The document is written from the perspective of a management professional with an honours degree in journalism and 35 years experience as a media specialist, but also as a person who has lived with a serious long-term disability for 25 years and during the past decade has been an outspoken critic of the amalgamated health board system for its mismanagement of his home support.

The "new" system is examined in this document through the lens of a disabled homeowner who has been struggling to afford to live at his modest home.

Newfoundland and Labrador's former Deputy Minister of Health, John Abbott, now the province's Minister of Children, Seniors and Social Development, Minister Responsible for the Status of Persons with Disabilities; for the Community Sector; and for the Newfoundland and Labrador Housing Corporation, made it clear in 2018 that big changes were in the works

for the healthcare delivery system. He confirmed costs weren't sustainable and government needs to bring our national per capita health costs down 10 percent. NL is spending 25 percent more than other Canadian provinces. John Abbott said he'd put every facility, service and profession under scrutiny. Government served notice the status quo isn't acceptable.

The Deloitte Executive Report of July 2016, the public information-gathering and capacity-building sessions held by the Newfoundland and Labrador Coalition of Persons with Disabilities and the Newfoundland Labrador Association for Community Living, governments' strategy reports and academic publications all give prominence to the concept that disabled people have equal rights and are entitled to making the decisions that determine their lives.

This central theme will form the tone for the "new" system, which theoretically allows disabled citizens to have control of where and how they spend any public funding.

The report from Deloitte is presented as the pivotal document in the five-year plan. *Their conclusions make it clear: living at home is considerably cheaper than institutionalization.*

However, the Deloitte document makes no mention of specific assistance for disabled low-income householders, even though government is focusing on a healthcare system that will supposedly minimize expensive institutionalization and assist citizens to stay in their homes. Government has focused

...the Deloitte document makes no mention of specific assistance for disabled low-income householders, even though the government is focusing on a healthcare system that will supposedly minimize expensive institutionalization and assist citizens to stay in their homes longer.

on this theme as far back as 2012, when they released the consultation document entitled *Close to Home: Vision for Long-Term Care and Community Support Services*.

Rights of the disabled supposedly frame the current thought about legislation. "Policy structures and instruments should progress towards supporting individuals with disabilities to exercise rights and citizenship by supporting the articulation of choices and building the capacity to act on choices (Prince, M. J. (2009). *Absent Citizens: Disability Politics and Policy in Canada*. University of Toronto Press, Publishing Division). It is also advocated that disability budget decisions should not only be disability responsive, but should also: "enable Canadians with disabilities to realize full citizenship."

Events in real life don't currently match the ideologies and policy as presented in government documentation. Personally, I am currently expected by regional health authority (RHA) Eastern Health to maintain a home and support my homecare workers on an income \$10,000 below the poverty level.

(It is currently common practice to refer to home support workers by a variety of terms: homecare workers and person-

al support workers are also used interchangeably. For the purpose of this report, all terms for home support workers will also refer to the same general job description.)

Until recently, this included paying for driveway snowclearing to accommodate homecare workers, who are funded by the government. Before COVID-19 I was also expected to supply their hand sanitizer. All of this on a Canada Pension of roughly \$12,000.

I still offer the agency's employees free Wi-Fi Internet and their own television to watch. This is the only way to retain employees in today's competitive market. The agency has no initiatives for hiring, training or employee retention, all areas highlighted in the Deloitte review.

By all evaluations disabled homeowners are expected to lower their expectations of life while representatives of the regional health authority stand idly by and take large salaries,

If the concept of total quality management is foreign to the bureaucracy, that casts an even harsher light on what they have been doing or more correctly not doing since the 1990s. Lack of knowledge on this subject would reflect: a lack of information about policy plus ineffective communication within departments.

comprised of taxpayers' money. I've written extensively about my experiences in the shadow of the Sunshine List.

There is a major disconnect between theory and practice. My report operates with the understanding the regional health board system in Newfoundland, given the experiences of marginalized disabled homeowners, has *not met its original goal to improve services in the province and make them more affordable for taxpayers*. The general consensus among the population of Newfoundland is that the health board amalgamation process in the early 2000s was ill-advised, as opposed to positive data evaluations or optimistic documents prepared by individuals funded by government departments or health boards themselves.

Debbie Forward, head of the Nurses' Union of Newfoundland and Labrador, wasn't aware of the IF initiative when this report's writer asked her to comment about it at CBC Television's Critical Condition forum in St John's on May 31st, 2018. However, she responded to the second question about whether health services were being delivered better under the previous health boards or the current amalgamated regional health authority structure, by saying the answer *depended on who one was speaking to and what day of the week it was*. She said there were errors in the implementation of the structure that are causing problems to this day.

Government says it is proposing a vision of the state of the future of personal home support programs based upon leading practices, insights from other jurisdictions and anticipation of future demand. Beyond some discussion of residential housing, however, the Deloitte report makes no reference to housing issues for disabled homeowners.

Work is supposedly already underway to review how the

province deploys its health services. These improvements will supposedly modernize service delivery of these community support services, support appropriate utilization of health care resources and be more client-centred.

Meanwhile, the reality is no improvements have been made and the environment continues to deteriorate under the stewardship of those responsible to make the changes and who appear to be negligent and/or lying about current conditions.

When I heard yet another report had been commissioned in 2020, I was shocked but not completely surprised.

From this report's writer's experience, promises of change in Newfoundland and Labrador's healthcare system emerging from the 2021 Health AccordNL that will in any way involve the regional health boards are certainly viewed with deep suspicion by the elements of the disabled community who are existing on the financial margins.

The \$250,000 Deloitte review from 2016 is written in a style laced with bureaucratic, administrative terminology and acronyms, which makes it challenging and tedious to read and understand. More than anything else it is a complicated general snapshot of the personal home support system, with data provided to attempt to give a positive picture of the size and scope of the program.

The report has an inherent weakness:

It uses intentions, responsibilities or prescribed tasks as descriptions of what actually occurs in the system. For example, because an amalgamated health board, known as a regional health authority (RHA) says current operational standards define provincial home support program goals as including: "that individuals who meet program admission criteria have the support and services they need to live and develop fully and independently within the community in keeping with their assessed need; individuals have choice in how they live..." it doesn't actually make it a true or even accurate picture.

It is far from the case from the perspective and experience of this report's author. It is a hypocritical statement at its least.

Deloitte says a small client survey of 130 showed high levels of satisfaction with the program as it actually exists. One must keep in mind, these surveys were completed by people who had the resources and time to respond and furthermore, the program has more than 7,000 clients. This tiny number is hardly indicative of anything.

Their conclusions are drawn from within the scope of the survey. This survey does not include any research of criticisms of the system that have occurred in the public forum. Critics of the system were not sought out. *The Deloitte report assumes that the RHAs are satisfactorily meeting the conditions of their own existing standards because they say they are, which is not necessarily the case just because it is written.*

However, in almost the same breath Deloitte also says they have no complete data set to support belief in the results of the survey.

Deloitte makes it clear there are no consistently-reported key performance indicators or an overall performance framework

to guide delivery of the program or measure its success. The survey is in effect irrelevant. Their report states: "the lack of a systematic and integrated management information system to support timely and reliable reporting by RHAs inhibits effective program monitoring, planning and budgeting."

The very necessity of contracting Deloitte for \$250,000 to develop such a document prompts questions about the state of the regional health authorities and why they are unable to maintain their responsibilities. It reflects lack of depth within the organization and inability to understand processes they are responsible to the taxpayers for maintaining and improving.

The fact that personal home support programming in a province with a population as small as Newfoundland and Labrador should be in trouble financially more than a decade after health board amalgamation to such an extent Deloitte had to be hired raises some other serious concerns about competence and systemic failure.

The further fact that in five years little or no progress has been made on the promises made by the Deloitte review is even more troubling.

In light of this, the very existence of Health AccordNL, another "direction document" by the same group of organizations is an unnecessary, costly absurdity.

Given this context, the Deloitte report in itself is a stinging indictment of the failure of Newfoundland and Labrador's regional health authority system to live up to what it originally promised in 2003. My report exposes the organization as uncoordinated, lackadaisical, anti-learning, regressive and close-minded as of any of the "bureaucratic silos" that were singled out for criticism in government's Way Forward document.

The Deloitte report suggests some type of quality management structure, echoing what I have been saying for over a decade: "Implementing a performance management framework would improve the ability of the Department of Health and Community Services (HCS) and the RHAs to monitor and evaluate the program's outcomes. A focus on performance measurement will mean the program benefits from continuous improvement as outcomes are measured regularly..."

Any report on the government's proposed individualized funding and other changes to the home support system must ask the question: *do you trust these individuals in the regional health authorities or the Department of Health and Community Services to achieve anything described in glowing generalist terms in government documentation?*

The daily realities experienced by disabled adults who own their own homes was not mentioned in the Deloitte document. Government has said it will expand the role of personal care homes and expand residential services. The expansion of residential services may be a solution for some individuals with intellectual impairment and would definitely eliminate travel between clients for home care agencies. However, in expanded form, an individual's home would no longer be a residential setting, rather it becomes an institutional one. The regional health authorities' systems are imposed by the homecare agencies.

In a statement to the media during December, 2017, former Deputy Minister of Health and Community Services John Ab-

bott said: "we want to accelerate what we're doing here to become one of the leaders in the country."

The idea that a progressive, individualized funding-based home support program that would be flexible and controlled by a disabled homeowner can be delivered by the same set of individuals now responsible for a cascade of systemic failures is not rational or believable. At this time, anyhow, the idea they could become leaders anywhere else but in their own minds is fraught with serious doubts.

Any number of total quality management or quality improvement systems could have at least been an attempt to address these problems before they arose.

Personally, I was responsible for communications and publicity for a quality management initiative in the post-secondary education system in the mid-90s, working directly with Douglas Fowlow at what is now College of the North Atlantic headquarters in Stephenville. The concept of total quality management should not be foreign to anybody working in Newfoundland and Labrador's bureaucracy.

If the concept of total quality management is foreign to the bureaucracy, that casts an even harsher light on what they have been doing or more correctly not doing since the 1990s. Lack of knowledge on this subject would reflect: a lack of information about policy plus ineffective communication within departments. This is alarming.

Background

More than a decade ago the government of Newfoundland and Labrador announced its intentions to modify how supports for the disabled are to be funded and delivered, with changes originally suggested in the Close to Home Report in 2012, and a further announcement in August 2016, based on the presentation of the Deloitte Report on Health and Community Services, delivered to government in July 2016. The review was to “investigate reasons for the significant growth in caseloads and program expenditures.”

Five years ago, Provincial government said Newfoundland and Labrador’s \$3-billion per year health system is heading for a major shakeup. The cost of our system is at a place now where we really can’t afford it, said both the minister and deputy minister of Health and Community Services.

On Dec. 23, 2016, the province signed on for federal funding in home and community care, including palliative care and mental health/addictions. Over 10-years (2017-18 to 2026-27), there will be combined funding of an estimated \$160.7 million (\$87.7 million for home care).

The Provincial Government said it would use the Deloitte report to identify initiatives that can be put into action and to support commitments in the provincial Long-Term Care and Community Support Services Strategy. According to government, the starting points are:

- Streamline the financial assessment process;
- Align policies among the regional health authorities in program delivery;
- Improve standards to reflect best practices in home support;
- Develop a performance management framework to monitor and evaluate outcomes; and
- Establish agency agreements with service providers to increase accountability and oversight.

As a first step, government announced it would implement what is referred to as an Individualized Funding Model (IF), also known as Action 2.11 in the Close to Home document in the current governing political party’s Way Forward strategic planning document.

They said they would develop this new system for funding citizens availing of provincial social programs and services, termed within the public service as “clients” and implement it in 2018. This did not happen, at least in the eastern region of Newfoundland. The assessment process did not change in 2018. A Support Plan Section, 5.20, was added to government’s manual “Provincial Home Support Program Operational Standards” on July 15th, 2017. However, I have not been approached by Eastern Health to develop a support plan.

Single Point

For ease of understanding, I have organized the examination of the elements of Community Support policy into smaller sections.

The central element of the individualized funding model (IF) involves what is called: “a single point of access,” utilizing current resources, which are generally controlled by the regional health boards and/or government departments. Financial assistance for individuals is currently dispersed over a number of

programs offered across several departments with varying application processes and eligibility requirements.

Streamlined Plan

IF’s starting point was supposed to be a streamlining of the financial assessment process. Similar to how the model is implemented in other provinces and countries, individuals will participate in developing what are known as “support plans,” which would identify their needs and the funding required to meet the budget. It is supposed to be structured so an individual will only have to do one assessment, and going forward shape their funding needs from that assessment.

This new model theoretically reduces duplication of services and administrative costs of providing supports through multiple programs. In addition, reports from other jurisdictions show this approach to be cost-neutral to cost-saving.

The Assessment Nightmare

In 2019, the financial assessment package of forms required by disabled individuals to be completed in order to qualify for assistance was modified to centre around the federal tax assessment of the client, that is, their income. The program is no longer concerned with the financial burden already on its clients and now requires only the tax assessment and proof of spending on heating and electrical. *Expenses such as property tax, telephone and online access are no longer considered by the government as important to the finances of a vulnerable, low-income citizen of the province.* Insult on top of idiocy.

Regional health boards’ Financial Divisions had long insisted on completion of a cumbersome 15-page package of forms every year for individuals receiving home support. *Since the amalgamation of health boards in 2004, I was personally notified social workers and counselors were no longer permitted to assist clients with paperwork. This effectively downloaded all of these tasks to homecare workers, friends and family of the disabled and ultimately the responsibility rests with the disabled “clients” themselves. During a 2018 information session, held by the COPD and the NLACL, participants said the assessment was “not working.”*

It hasn’t been made clear to Newfoundlanders and Labradorians if the focus on income is what the Deloitte report meant by streamlining the financial assessment package. Unfortunately, the assessment process still *disregards critical areas shared by disabled homeowners on marginalized incomes, such as yardwork and property taxes.*

Personally, I have been writing about this problem for more than a decade, publishing open letters and circulating them to a target list of disability groups, government and media. In 2016 I wrote a comprehensive set of articles about living with disability in Newfoundland and Labrador and published them online. *It once again detailed the pointless, time-wasting and counterproductive policy of repeating the same arduous assessment process every year.* Although Danette Dooley’s feature about these articles, the Stationary Hobo, was published in three Newfoundland newspapers and the links received 1200 clicks, *no interest was shown by any disability organiza-*

tion, government, homecare agency or RHA – and all were on my distribution list.

An honours degree in journalism combined with more than a quarter-century of experience has given me observational skills and no hesitation to ask the uncomfortable questions. One of my favourite quotes about the assessment process comes from a Financial Division assessor, who told one of my sources: “I hate the work but I love the money.” In an open letter a few years ago I detailed the assessor who had become so well-to-do charging for overtime on this process they bought a certain model of Audi from Halifax, sight unseen, because the model contained the initials of their name.

It should also be noted the homecare agencies claim to be hamstrung by an assessment process every year.

Public Information Sessions

The provincial Coalition of Persons with Disabilities (NLCOPD), a pseudo-governmental group funded by the Health and Community Services Department, and the Newfoundland and Labrador Association for Community Living (NLACL), a nonprofit organization that represents individuals with intellectual disabilities and their families held a series of public information sessions and what were referred to as “capacity building” workshops across Newfoundland and Labrador during Autumn of 2017.

Personally, I had extreme difficulty getting involved with and contributing to these sessions. Initially, after contacting the organizers, I thought was scheduled to go to a session in Carbonear or Bay Roberts but did not hear back from an email. My responsibilities as a disabled homeowner with little resources took precedence and I was too busy to send follow-up emails. When I heard back it was indicated there would be a session in Clarendville. This was also cancelled. Finally, a few days before the last sessions in St. Johns, I was given a list of times and dates over the phone, where I could listen in or contribute via teleconference. I cannot hold a pen to write because multiple sclerosis has ruined my hands. I tried to read out the times and dates and details to another person, but I was not able to communicate the hurriedly-assembled information correctly.

As a result, I was only able to listen in to one of the Bally Haly sessions. The quality of the line was terrible. Fortunately, I’ve managed to cobble together a binaural headset. Anyone reduced using a handset would be unable to hear anything. Among other things, I had to listen to people talking about how good the muffins were, other teleconference participants going to the bathroom and radio signals cutting in.

I was told by the organizers I could only “listen in,” but it didn’t take long for me to realize I did have an open line into the event. I did a little whistle test to see what level they were getting on the other end and it was loud enough to irritate the organizers, enough so they scolded me to mute my telephone. That bunch, living large having their “baby’s day out” on the taxpayers’ dime, this cadre of the clueless, scolding me in their ableist vacuity. Mind now. However, no measure was taken to amplify phone lines so all attendees could participate.

Unheard Voices

I have an extensive background in audio recording and radio journalism. Much of my field work with CBC Radio in the early 90s was done via phone. I’ve been involved with conferences and board sessions in organizations as varied as the Writers’ Alliance, College of the North Atlantic, Robinson-Blackmore (the province’s newspaper chain from the 70s to 90s), and my own agency, which included amongst its contracts the province’s first distributed learning website.

...the coalition and the association had brought an Australian man, Layton Deigh, as an individualized funding expert, although Mr. Deigh repeatedly told the room at Bally Haly he was not an expert. And the facilitators from the coalition and the association kept insisting he was an expert. It was an awkward interchange, bordering on the surreal.

My observations are meant to be personally critical of the organizers. They did the worst with what they had to work with. Which in reality, obviously produced very little of worth to a disabled person in my predicament. It just goes to verify the sessions were obviously a process of “going through the motions” and there was never any serious willpower to comprehensively bring the issue to the public. *Representatives of the RHA were noticeable by their absence.*

This would lead an average person in this society to conclude it was obviously fixed to be a propaganda exercise with no interest in public input. It had already been done. *The individuals staging it were little more than tour guides.*

Later, I had the opportunity to discuss the sessions with a representative of a homecare agency who had attended. *This individual was also one of the stakeholders listed as contributing to the Deloitte report itself.*

There was a high level of disappointment, because no policy, legislation or framework was developed. I was informed of two specific exercises, one of which was using a box of random toy items to communicate stories. The other one involved an individual listening to a story from another individual and then parroting it to or third individual. “What are we doing here?” was my source’s reaction, “there doesn’t seem to be any point to this.” These two exercises were most likely an attempt at some sort of popular education technique, although for those to be effective, there have to be stringent parameters. In the early 90s, I was fortunate to have completed a weekend-long popular education course with the provinces popular education pioneer Bruce Gilbert. *Popular education techniques are especially effective when used properly, and a pathetic, lazy waste of time when they are not.* These appear to fit into the second category of uselessness.

The only take away my homecare agency source said anybody communicated amongst themselves, was that **Newfoundland and Labrador was going to be adopting an Australian model of individualized funding.** Honest to God.

This was because the coalition and the association had

brought an Australian man, Layton Deigh, as an individualized funding expert, although Mr. Deigh *repeatedly* told the room at Bally Haley he was not an expert. And the facilitators from the coalition and the association kept laughing like foolish children, insisting he was an expert. It was an awkward interchange, bordering on the surreal.

I had to explain individualized funding to the person in charge of the homecare agency being paid public funds to supply my service, who's now taken a senior management role with another provincial homecare agency. Taxpayers paid travel mileage and bought meals for people to attend an information session, and this competent professional wasn't able to learn a thing first or last. I explained what the Deloitte report was about. Organizers were unable to get that across. I kid you not.

As mentioned above, this person is actually listed in the stakeholders group for the Deloitte report itself, but have demonstrated multiple times the management of the RHA and the Department of Health and Community Services have neither the skillsets nor intellect essential to oversee the safe operation of a homecare agency.

It should disturb people to realize many in charge of home care agencies don't know but they are working for a fast food restaurant chain.

Health Authority Failures

My complaint about the assessment forms was loudly echoed. Another important point I heard from the comments at the session: "nobody knows how they (the RHA's financial divisions) come up with the number they come up with."

Mr. Steele's book *What I Learned in Politics* serves as verification that the modern Canadian politician in the party system is almost completely concerned with re-election, at the behest of and under orders from the party executive. He discussed this subject in depth on the Power & Politics program of CBC News Network in May of 2018.

Eastern Health had continued to reduce my heating supplement every year from 2011 to 2018. Lower funding means I'd been forced to cut spending on heat and light. When I'd been forced to spend less and lower the heat, the next year the RHA dropped the amount of my supplement again. Four years ago, *I asked to be reassessed and in their refusal letter, their figures didn't even match the numbers on their cheques. I wrote about this to my MHA, the regional health authority and the premier's office. I never received as much as a phone call, let alone an explanation.*

In 2019, my assessment slightly increased my supplement back to 2013 levels. Was this a one-off? There was no explanation, once again echoing what I heard in the 2017 sessions. Or was this a product of the so-called streamlining? Does every individual get a flat rate now? Again, no explanation.

The chaos returned in 2021, though, when my heating supplement was reduced by nearly \$1000 with no explanation, although my expenditures had not varied that much year over year. My MHA is currently looking into the inconsistency for

me, but I do not expect a positive result from this process.

The People Up Above: A Chat With Premier Ball

Through a personal reference on social media, in 2017 I managed to get a brief discussion with the premier about this RHA-created nightmare. Although the man was kind and generous in his concern and empathy, (he's kissed a few hands and shaken a few babies before), he explained to me that our parliamentary representatives are too busy with their day-to-day tasks to know about the troubles and tribulations of those living on the margins. They aren't exposed to those stories.

This is the excuse I had to listen to from yet another rich man in politics. And this guy knows my brother-in-law. No, he does, he does. Don't worry, if the shoe's ever on the other foot, I'll show him as much mercy as he showed me, for sure. *Heaven knows what cabinet ministers are talking about when they are sharing a joint in the parking lot of the Gander Hotel.*

The premier told me he would communicate his concerns about RHA errors both to his executive assistant, who had been approached previously and also his "man in charge" of health boards. *However, as I write this report, I have heard nothing from either one of these people. I even mentioned it in the candidates' debate during the 2019 provincial election, when I stood for office in Terra Nova District under the NL Alliance banner. Not to put too fine a point on it, but nobody in power gave a shit.*

The premier's reasoning gets no traction in the home left to me by my father, a World War II veteran of Newfoundland's esteemed 59th Heavy Artillery regiment. *My parents were of the generation that used their skills and busted their asses to make this place better. For what, so the premier could call their crippled son on the telephone and throw an excuse at him that the reason nobody would help him was because the current generation of representatives don't know what they're doing?*

One can appreciate the schedule of CEO positions like Mr. Ball held, but it seems a weak excuse for individuals further down the chain but still deemed worthy enough of being paid more than six figures a year of the population's money. During a short stint teaching journalism in the province's college system, I wasn't paid a third of what they are given and had a vastly better understanding of conditions on the ground in this province. *I mean, if that's the excuse the premier had, that was a pretty pathetic bunch of halfwits out there.*

That is why I stood for office in 2019. *I really wanted to get elected so I could go out there and show a guy in a wheelchair on disability pension can do better.*

I know former Nova Scotia cabinet minister Graham Steele from our time at King's College Student Residence in Halifax in the 1980s. Mr. Steele's book *What I Learned in Politics* serves as verification that the modern Canadian politician in the party system is almost completely concerned with re-election, at the behest of and under orders from the party executive. He discussed this subject in depth on the Power & Politics program of CBC News Network in May of 2018.

Special Lie of the Day

This is what the RHAs told Deloitte: "All financial data related to clients, including approved service hours, client contribution levels and financial subsidy levels are keyed into the Client Referral and Management System (CRMS) Pay Module, which is intended to support the financial assessment and payment processes." From my experience and what I have heard at the consultation session, disabled individuals in the province would take exception to this assessment. It is an area that definitely needs to be carefully investigated for inconsistencies. Honestly, the RHA position sounds made up.

There is an overtone of excuses from the regional health authority, an overtone of making it look like something was accomplished when in fact many elements of how the programs are being delivered by Eastern Health are case studies for inertia and frame the health authority's record of inadequate, counterintuitive communication and poor relationships between bureaucracy and the citizens they call "clients."

Give 'em an Inch, They'll Take Your Feet

Nearly a decade ago, the health board started refusing to provide my foot care and I nearly lost a toe. This happened twice. The second time I was forced to go on the operating table to have my toenail removed – fortunately, the surgeon said it would recover, so I was saved that horror at the last moment... The first time, the story was picked up by the media and Dr. Harold Crewe was quoted in the regional newspaper as saying the Health Board was "ignoring me and hoping I would just go away."

And the man was no friend of mine, he was only my doctor, so he wasn't lying to protect me.

RHA Conflict of Interest

The supposed IF support plans will be developed by the individual and what they are calling their "support team." From listening to the Bally Haley session, government will have us understand the "team" will also have to be made up of family and friends and homecare workers. It was interesting to hear and read that the personal planning of support needs and service funding and their delivery (RHA, HCS) should be "separated in order to rule out conflict of interest." Is this an assumption of bias and discrimination from employees of the regional health authorities and the government departments themselves? What gives?

Social workers are rendered useless if they can't be trusted to assist a disabled person with their budgeting. It is another stinging indictment of the regional health board authorities that the individuals they are mandated to assist can no longer trust their taxpayer-funded employees.

A question often arises as one re-reads the Deloitte report: who are these people and why can't they get it together? Why is there such desire across the board in Newfoundland and Labrador's private sector and in the general population to, as Roger Waters once said: "whip those little ingrates into shape."

Para-What-Now?

The Deloitte report mentions this: "Delegating reassess-

ments to supervised RHA paraprofessionals to improve RHA staff productivity and service capacity."

This brings up more questions: what does government call a paraprofessional? Will this introduce another level of bureaucracy to the process, a taxpayer-funded group of individuals who neither work for the government or for the regional health authorities? Who will be responsible for oversight of that group? Unionized or not? Will the health boards train them to use parachutes? I don't think that is going to end well.

They also said clients surveyed also have a high level of satisfaction with the program."

In a phone survey of only 130 individuals from a program of over 7000, is it fair for government to make such a general statement?

No Plan For More With Less

The NLCOPD and NLACL were told no additional money will be put into the new IF model. The government has suggested to them there may be overspending in other areas. Unfortunately, that doesn't sound much like a business plan.

Are we to take this to mean the Department of Health and Community Services will find adequate savings to substantiate the new program by fixing the mistakes of the old? According to government, starting from point zero every year with every disabled individual is costing government too much money. *At the same time, the amalgamated health boards were unable to live up to their promise of making the delivery of services more cost-effective, and had over a decade to carry out their mandate.*

Mere months before the implementation of a new program, disabled persons had no qualitative or quantitative estimation from the department or the RHAs as to what the financial reality of IF would mean to them.

Although the new program was supposed to begin in 2018, there was no indication from government what shape it would take. Assessment forms in 2018 were the same, but modified in 2019, *the streamlining amounting to making yearly income tax assessment the key piece of documentation.* Previously, detailed accounting of expenses was required, with clearance given to the client's bank to verify pension funding and account activity. Now clients must provide Canadian Revenue Agency Notice of Assessment and sign request forms to verify utilities. Far from meeting the promise to allow disabled citizens more control in their lives, the RHAs now totally disregard and neglect the financial challenges of the most vulnerable.

I called my local assessment officer at Eastern Health in April 2019 to verify I had a complete package of forms, as two were missing in the numerical order and there was no explanation in the cover letter. When I asked her to verify that account access was no longer necessary, she said "the bank doesn't let us do that anymore." So I don't really know what that's about.

Supposedly the findings of the public consultation sessions were meant to assist in the development of the new structure. However, when I discussed the sessions with a homecare agency representative, they had been given no indication any goals have been reached in that area. In fact, they appeared

totally ignorant of the Deloitte review's policy and processes.

Government has given no indication of any projection of how much money could be recouped by eliminating unnecessary taxpayer-funded positions as financial assessors and social workers or even if they have the wherewithal to remove these people from the system. The Newfoundland and Labrador Association of Public Employees (NLAPE) contract contains a four-year hiring freeze.

A Survey in Distraction

When the Deloitte report was released, government was quick to say "report on the provincial home support program released today shows general consensus among stakeholders that the program is meeting its goals." They also said in their media releases "the report shows that clients surveyed also have a high level of satisfaction with the program."

The regional health authority and health and community services department establishment is again attempting to manufacture consent for whatever move they make next. In light of any future failure, they can fall back on saying they "engaged in a successful process that allowed them to move forward," in the fashion they chose. Misinformation at best, but presents as a textbook case of disinformation.

In a phone survey of only 130 from a program of over 7000, is it fair for government to make such a general statement?

It is seen with large amounts of trepidation that on the basis of a small, narrow client survey government has found a general consensus among stakeholders that the program is meeting its goals, and clients surveyed have a high level of satisfaction with the program.

Lack of Real Input

The noisiest and best informed and experienced of the public critics were not consulted or invited to contribute directly. It is incumbent on government and the RHAs to include all points of view, especially the harsh indictments and uncomfortable observations of the system's shortcomings. The picture is suspiciously rosy, if on the other hand the system is vastly over budget, as the government also claims.

I have already detailed above my experiences with community support system management who didn't have a level of skill or intelligence necessary to meet their job responsibilities.

Deloitte didn't consult me. I don't particularly care, It's common knowledge among my family and friends the level of neglect displayed towards me by RHA personnel who obviously would like to see me silenced permanently. I'm busy just keeping my head above water. The problem is that government, the regional health authority or any of their supporting organizations didn't speak to anybody remotely like me, even though myself and others have been making a substantial amount of noise publicly.

Only those close to the system were consulted. The individuals most likely to fall through the cracks and those operating outside the confines of pseudo governmental organizations like the NLCOPD or volunteer organizations like the Newfoundland

and Labrador Association for Independent Living have no say.

Government and RHA may be afraid of facing the criticism. They don't want the truth made public. Ironically, they refuse to validate the people who they are tasked to assist.

Eastern Health staff who are supposed to keep individuals like me in the loop never did and most likely had no clue the consultation process was going on. Even if they had some outside idea, there is a very large possibility they probably couldn't articulate any knowledge of the details.

TQM and CQI

Ironically, every opportunity was given for public sector management to invoke quality management protocols more than a decade ago. For example, I was responsible for text and design for promotion of a quality management initiative in the college system more than 20 years ago, based out of college headquarters in Stephenville, proposing Constant Quality Improvement and Total Quality Management protocols, working directly with Douglas Fowlow, president of Western Community College.

Government had to pay the analysis firm Deloitte to strip the data for its 2016 report from the RHAs. If a quality management system had already existed, this would have already been self-generating material available at a series of keystrokes. The infrastructure for this type of data gathering and sharing already existed two decades ago.

There would be no need to bring an analysis firm into the system and pay them more taxpayers' money. Information technology solutions for the health boards of the time were brought to the government's attention practically two decades ago by among others, the Discovery Region Smart Communities team in 1998. *I managed all media for that multi-community initiative and assisted with the medical data sharing proposal. Ask me some time and I will tell you about the prize being awarded before the date the winner was to be chosen. To paraphrase the Bard: a history of rotten stuff around here.*

Beyond Blunderdome

The upshot of the consultation scenario was the government financed an individual from Australia, by the name of Layton Deigh to participate in the so-called consultation sessions as a knowledgeable resource. Australia has an IF system. The organizers tried to frame him as a "global expert in IF," although he had to awkwardly deny this a couple of times during the session I listened to. Deigh was basically just a guy from Australia with a disabled child and he repeated this fact several times.

In Australia, the system pays for disabled individuals to receive services from sex industry workers. There is a fascinating documentary about this called Scarlet Road. Up until now, I've not had the opportunity to discuss how radically different our society and cultural setting is from Australia.

It would have been far better to avail of a real expert and a critic from within the Canadian system to join in on a panel structure. Forms, guidelines, structure another details could have been developed by that method, and brought to Health and Community Services, which could have eliminated admin-

istrative steps and help streamline the process. Suggestions and complaints or touchy-feely public servant busy work don't achieve any concrete goals.

A representative of a homecare agency I spoke with about the sessions told me they left with the impression Newfoundland and Labrador was adopting an Australian system.

And that's about all they knew about it, according to her.

No Real Opportunities

In a similar way to how a small survey can make it look as if the current system is functioning properly, the system tries to make itself look good by taking credit for coming up with solutions by saying the Deloitte report identifies opportunities for improvement that the Provincial Government will consider and implement over the short, medium and long term.

"While a client survey by Deloitte suggests a degree of satisfaction and effectiveness in the program as it currently exists, there are opportunities for improvement," said John Haggie, Minister of Health and Community Services.

The regional health authority and health and community services department establishment is again attempting to manufacture consent for whatever move they make next. In light of any future failure, they can fall back on saying they "engaged in a successful process that allowed them to move forward," in the fashion they chose. Misinformation at best, but presents as a textbook case of disinformation. Hard questions haven't been asked, they haven't spoken to hard people. There is some alarming evidence that people responsible for the process up to this point are "incredible mediocrities," a term coined by the commentator Chris Hedges.

Lack of Media Coverage

What's referred to as the "mainstream" media is under-resourced and understaffed and can barely cover the weather or the latest stabbings, animal abuse and car accidents. As a result, the quality of communication transfer from reporters has diminished somewhat.

Issues such as regional service district planning and changes to the health system both come with intense amounts of jargon-laden and bureaucratically-written documentation, time-consuming to interpret and write stories about in a way that provides adequate context. They are doing the best they can, but that is a subject for a totally different report.

Analysis

The provincial home support system proposed by Deloitte for Newfoundland and Labrador is appraised and analyzed in this review from the perspective of an adult with disabilities who is struggling to afford living at home and has suffered substantial harm as a direct result of the behaviour of a regional health board and homecare agencies.

Information for this report comes from the Deloitte's Home Support Review, government's Way Forward and Close to Home documents, Working Document to Inform the Development of an Individualized Funding model in Newfoundland and Labrador by Yirong Qin, Memorial University of Newfoundland, Provincial Home Support Program Operational Standards, text from NLCOPD and NLALC, newspaper stories, notes from the Capacity Building session, St. John's, discussions with a wide range of individuals in the system, personal experience and published articles and open letters.

The Deloitte report specifies: "adults with disabilities reported lower satisfaction relative to other client groups across all measures."

It may well be because some of these individuals can speak for themselves, unlike some of their less advantaged counterparts. And because they are struggling to hold on to their homes, even when government boasts its policies keep people in their homes and that saves money.

This report is divided into the four main areas detailed in the documents referenced above:

- Assessment/Funding;
- Team Support/Outcomes;
- Homecare Agency Realities;
- Health Authority Realities.

Part 1

Assessment / Funding

Introduction

Upon examination, the only obviously beneficial concept of the proposed individualized funding system for all disabled persons is the "single point of access," the starting point for the disabled individual in the "new system." This is a change in policy from the existing system, where the individual is financially means assessed every year. It makes eminent sense to streamline the assessment process. For years, the process has appeared to disabled clients as a make-work project for well-paid publicly-funded accountants, working for the regional health authority. *However, as of 2021, I am still being assessed every year and have not been notified this will change.*

From this single assessment process, the client will supposedly come up with a budgeted plan for their life, known as an Individual Support Plan, using a personal support team of friends and family. *As presented in current documentation, there will only be a financial saving here if hours are eliminated from RHA employees.*

Truths vs Fictions

Where the fantasy meets reality is the concept put forth by government that from a single point long-term assessment, disabled individuals will be able to exercise a level of control that permits them to shape their budgeting and finances and therefore improve and direct their lives, allowing them to have goals and dreams, as specified in the United Nations Report On The Lives Of The Disabled.

According to the documentation that surrounds government's plan to change the system, supporting principles will include profitability and flexibility across departments, agencies, regions and the client's life span.

Profitable to whom? How will this be measured? And by whom? When? Nothing's been done for five years.

Under the government's "new" model, clients will supposedly be able to tailor their funding based on the supports they require to aid in the development of daily living skills; improve care of self and home; find or maintain suitable housing; support access to recreation and other community resources; and, increase their capacity to undertake paid or volunteer work.

This "Blue Sky Thinking" appears to be somewhat beyond an over-reach. Government says no extra money will be put into the new system that didn't exist in the old one.

It begs the question: how is a regional health authority system that is regarded by many private citizens in Newfoundland as an expensive systemic failure going to accomplish these goals, moving forward from the general realization that as was expressed by Newfoundland and Labrador Nurses' Union President Debbie Forward to me publicly there is no consensus that amalgamation of the previously existing health boards in 2004 makes the delivery of health services any better than under the previous boards.

Government and the RHAs are already behind schedule on the individualized funding initiative. The pandemic of 2020-21 has certainly put timelines further back.

Existing Hypocrisy

From the perspective of a disabled homeowner, the question is clear: how will we establish long term financial level of need in the proposed IF system? It is not clear if new criteria will be adapted or not. Will it differ from previous process of assessment? In the current system, in the early 2000s I had rent totally subsidized by the RHA. *However, I had to have a public fight with them in the media over Foot Care before I found out rent supplements were offered and I found out because the money just showed up without notice.*

Although RHAs pay landlords over \$1,000 monthly, when I moved into a home inherited from my parents there was no support. There's no structure to assist clients to live in their homes even when incomes are \$10,000 below poverty level.

I have lived in this predicament for over a decade, and as I mentioned earlier, until 2020 I was still on the hook to purchase hand sanitizer and snowclearing to accommodate employees provided by the RHA through a homecare agency, a

privately-owned company receiving more than \$10 an hour profit of public funds for every hour a worker was placed in a client's home.

The RHA, although well aware of my predicament, have not helped. It is almost as if they do not want me to succeed in a situation the government has already identified as being superior to institutionalization in cost and outcomes.

Absent RHAs

There is no evidence any organizational mechanism has been developed to match services with individuals. This protocol and process would be a crucial element of any administration developed for the new program. Simple data management would be able to underpin those elements of the system. The danger is the RHA system as it currently exists may be unable to accomplish this, as over the last decade and a half they have repeatedly shown an inability to accomplish coordination with the personal support resources that currently exist.

The failure of RHAs to fix the visibly-flawed assessment process does not bode well for a new system that promises to be more responsive. The technology necessary to facilitate the matching of supply elements with client needs and effectively track them has been available for decades and the health boards have failed to implement readily-available and easily-obtainable solutions.

In this current digital environment, it falls directly to the RHAs to show leadership and take responsibility for aligning and capitalizing on community resources. The health authorities have been shown the way in the Clarenville region by the CREST accessibility bus concept, but the health authorities have to be even more proactive and forward-thinking, reaching out to businesses and corporate interests and developing consistent framework to assist clients on a daily, permanent basis.

The RHA should long ago have taken on an organizational mindset that is more in tandem with local values and the ultimate responsibility to create value in the lives of their clients, enabling them to advantage of what they have to offer. They would be wise to revisit the concepts first pioneered by the region's Smart Communities Team back in 1998.

More administrative paperwork and/or less effective administrative paperwork only paves the way for even more slothful management waste.

Personal Perspective

I have consistently lived on disability pension at practically \$10,000 below the poverty level. I have spoken about this consistently for more than a decade to all levels. Publicly-paid individuals who could help, to a person looked at me helplessly or from the depths of ignorant arrogance.

The fact that government documentation surrounding the changes to home support blithely ignores tough realities and regards the regional health authorities and their home support management as a functioning status quo is a disquieting starting point for a disabled adult attempting to stay in their home.

Throughout the previous decade, the regional health author-

ity known as Eastern Health consistently reduced my heating supplement. This forced me to bring my heating cost down farther. When I spent less on heating, Eastern Health cut my heating supplement. These are the same health professionals who forced me to pay out-of-pocket for snow clearing so publicly-funded employees can get to work. I also had to supply hand sanitizer and toilet tissue for homecare agency workers.

Five years ago I requested a reassessment from the health authority and they didn't even get the figures correct. I sent this information to my MHA, the premier and the regional health authority's customer service. I explained this to my social worker, in the presence of another Eastern Health employee at least twice. Nobody bothered to help.

In 2021, Eastern Health reduced my heating supplements by nearly \$1000, unannounced and with no reasoning. My MHA's office is looking into it for me, but I hold out little hope.

Living and coping day-to-day leave me absolutely no time to do a bewildering stack of paperwork necessary to apply for grants any maintenance to my home. The regional health authority has been made aware they are forcing an individual to lower their expectations. Everybody in my family and my circle of friends knows it: the RHA and a series of homecare agencies have shown little interest in validating me as a person.

The regional health authority and health and community services department establishment is again attempting to manufacture consent for whatever move they make next. In light of any future failure, they can fall back on saying they "engaged in a successful process that allowed them to move forward," in the fashion they chose. Misinformation at best, but presents as a textbook case of disinformation.

No disabled homeowners' realities were mentioned at all in the Deloitte report or in the sessions I listened to or in any documentation I have been able to find. However, we are being told their status quo is effective.

Government's intentions are clear, the way they proposed to achieve this certainly the opposite.

Clear Record of Failure

Few in the province believe the regional health authorities are going to accomplish anything progressive to help disabled homeowners.

From the Deloitte report: "One of the key goals in providing home support services is to maintain clients in their homes and to minimize disruptions in their living arrangements. For adults with disabilities, there are often greater challenges in delivering on this goal due to their complex needs and limited program options."

What I have found most limited is the vision or common sense of the caseworkers and social workers. They have been given multiple options by more than one individual including myself and there was absolutely no will on behalf of anybody else to even try to move an idea up the chain. *As an individual with extensive background in management and education,*

they appear to be actively attempting to do the least amount of work possible and take on the least amount of responsibility possible. They could however, manufacture a lie, an excuse or a complaint and do so in record time.

However, they never seem reluctant to put on a big smile and have their photographs pasted on social media taking credit for something or other. The president of Eastern Health even slithered out of his office a number of months ago to take credit for new parking spaces.

To be publicly promised choices and guaranteed a better existence, and then be faced with the reality of no funding or structure to support it, is disingenuous and misinforming,

It becomes apparent looking at the first dozen pages of this review in light of the Provincial Home Support Program Operational Standards Manual that the RHA Eastern Health repeatedly neglects its defining Goals (Section 1.50) "...individuals who meet program admission criteria have the support and services they need to live and develop fully and independently within the community assessed need. That individuals have choice

Ideally, the RHA would work with other departments, agencies and the private sector to improve basic elements of matching clients with improved support plans, utilizing information technology and also extending out into the community to access volunteerism and employment, however the evidence shows a systemic reality that is quite the contrary.

in how they live." And the Principles (Section 1.60) "...need to ensure service is appropriate to the individual. The home support service plan respects the rights of the individual to participate in the decision-making process..."

False Promise

Here is a description of individualized planning from the Deloitte executive report:

"In assessing the client's service plan the coordinator considers how access to other community supports are factored in by the community health nurse or social worker. Examples would include availability of day programs, residential alternatives and other community services so that there are other choices for the client rather than having to rely fully on the Program for their support needs. Such examples foster sharing of scarce resources to meet multiple clients' needs; as well, they have the added benefit of counteracting the social isolation experienced by many clients in individualized living arrangements. The realities as expressed by the RHAs is that there are generally few if any options in most communities and there is limited community capacity to mount these types of alternative community supportive services.

There is limited flexibility in how approved hours, especially personal care hours, can be utilized by clients and agencies. As mentioned above, this is particularly challenging to adults with disabilities and the Special Child Welfare Allowance Program (SCWA) population, who require other allowances and supplementary supports such as community inclusion and life-

style coaching. Expanding of the individualized funding model, which would provide a monthly budget or block funding to the client, would allow the client to use their approved hours and subsidy as they see fit."

Obviously, if there isn't enough funding to live a life with even the most basic expectations now, how could changing the terminology of the assessment create money or skillsets that aren't there? Are they are offering things they can't offer? Would it amount to expanded control of nothing?

Ideally, the RHA would work with other departments, agencies and the private sector to improve basic elements of matching clients with improved support plans, utilizing information technology and also extending out into the community to access volunteerism and employment, however the evidence shows a systemic reality that is quite the contrary.

Still Unclear For Homeowners

The Deloitte report also states: exploring approaches to allow for sharing of home support services between clients in particular geographical regions, such as Adult Day Programs and "residential options," could increase sustainability of agencies and home support worker efficiency.

Qualitative evidence demonstrates that Eastern Health is much more willing to approve services above the financial ceiling to alleviate acute and long-term care (LTC) system pressures. Is government's discussion of standardization working to improve that option, considering its obvious financial and so-

cial benefits? Will 24-hour home support be examined to improve its efficiency for clients and taxpayers?

Two Sides

There are two diverging lines of reality in the home support environment as it now stands:

Number one, the focus on the rights of the disabled, which as I've shown in this section and will show again in this document are being coarsely disregarded on a daily basis. In fact, I live in a world where the mindset of the RHAs toward the disabled is to regard them as a problem and nothing beyond.

Number two, the other line, which exists in opposition to the magnanimous doublespeak, is the intention of government to somehow find savings within their new approach. However, no quantitative or qualitative details have been provided as to how they will achieve this.

It is uncertain what type of administration has been designed for the new process. The assessment forms were a year late and were sent with no prior explanation about the changes. As I was an owner of a print shop where formwork was our bread and butter, the timelines here didn't match.

Conclusion

By taking a client-centered approach, clients of the IF model could develop personalized support plans, ideally with the help from case managers (planning facilitators), and receive funds to carry out those plans. Keeping in line with the Convention on the Rights of Persons with Disabilities, the IF model espouses the rights of individuals with disabilities to not only live in the

community, but also to have access to a range of support services which are responsive to needs and promotes community inclusion (United Nations, 2006).

The danger, as any professional old-breed reporter can tell you, are the dirty details hidden underneath the layers of soft, misguided, intentionally-vague bureaucratic language such as the kind that appears in government reports.

Unfortunately, changing the community support structure may become an RHA trainwreck if not implemented properly.

Part 2

Team Supports / Outcomes

Introduction

As we look further into the government documentation surrounding IF and changes to the system, it is critical to provide context to the ideas that are being put forward and to understand what words mean.

In the previous section regarding funding and assessment, I outlined the benefits of the single point concept, but also listed some of the factors that will interfere with successful implementation. The most prominent obstacle detailed was lack of skills, competency and organizational savvy within the regional health boards.

In the proposed system, the concept of long term planning for disabled individuals comes down to downloading what for decades was regarded as a social worker's job to what's referred to as a "support team," which has to be comprised of friends, family and we must assume homecare workers.

The first thing we should remember, is that social workers have refused to even help disabled homeowners with paperwork since regional amalgamation in 2004.

Disabled individuals, their families and the homecare agencies have been on their own for 15 years. Although couched in typical non-committal bureauspeak, all the support team concept means is legislation of long-term downloading of organizational management to family, friends and home care workers.

What Does RHA Do?

With little or no justification, assisting clients with paperwork became too difficult for social workers after the amalgamation of the previous health boards into the regional health authority model in 2004. As stated in the previous sections of this report, even after repeated requests for assistance to the health authority and the government, I have often not received as much as a reply to questions on a wide range of subjects, from assistive devices to homecare supports and foot care, let alone any knowledge, information or assistance.

As was demonstrated in the previous section, the RHAs are already operating in contrary to 1.5 and 1.6 of their own Operational Standards Manual for Home Support Programs as it concerns their responsibility towards the rights of their clients.

It begs a larger question: what do social workers do if not assist clients' work with the authority? The inability to provide

any assistance in the area which these employees are supposed to be knowledgeable appears to be beyond reason and can be perceived as an abrogation of health boards' responsibility.

Vanishing Spies

In 2017 I was informed by homecare agency administration Eastern Health instituted a policy of forcing every homecare worker into making a judgemental comment on the mental and physical state of their client after every shift and making a note of it for management. In 2019, the directive was changed so workers are now obligated to only log what they deem to be problems of a "medical" nature. They haven't told the public about this monitoring policy.

The workers forced to carry out that demand in my home are good people. However, they realize they have no skillsets that would make it ethical or moral for them to pass judgment to a pseudo governmental agency as to the competence of a fellow citizen. Neither of my personal care assistants is a psychologist or a counselor. Basically, Eastern Health forced my home care agency to engage in inappropriate behaviour. They have

Neither of my personal care assistants is a psychologist or a counselor. Basically, Eastern Health forced my home care agency to engage in inappropriate behaviour. They have been forced to spy on me and not tell me what they are writing in their logs. These notes are then submitted to the agency which submits them to Eastern Health.

been forced to spy on me and not tell me what they are writing in their logs. These notes are then submitted to the agency which submits them to Eastern Health.

I would like to know the name of the person who ordered them to do this. It appears as if laws were broken.

Why does Eastern Health do this? The Deloitte report and the current minister of health have both been quoted stating there was overwhelming satisfaction with the community health programs as delivered by the health boards.

It appears hypocritical to boast publicly that government and the regional health authority have it all under control and then download mental and physical health services to untrained personal care assistants at the homecare agencies. It is my understanding Eastern Health is forcing agencies to do this under protest.

When a dangerously incompetent homecare agency continually lied to my family and I nearly a decade ago, instead of apologizing and attempting to improve, they turned coward and dropped my service with no warning, leaving me, a person who is in a wheelchair and needs 24-hour homecare support to move, in a physically vulnerable position. Instead of taking me seriously and making moves to protect me, supposedly their "client," Eastern Health forced the new homecare agency's employees to keep a running set of notes on how they "thought" I was doing mentally and physically. Even though the agency was glaringly negligent, Eastern Health insisted on carrying out behaviour that cast aspersions on my character.

This went on for well over a year. They started it again within the last 96 months with no warning. And these are the organizations claiming they are looking after the rights of disabled homeowners?

This was a flagrant disregard of the Operational Standards Manual, Section 3.10 Individual's Rights and Privileges: "Individuals shall have personal rights and privileges which include, but are not limited to, the following: to be treated in a courteous manner, to have service provided by knowledgeable, trained, committed individuals, to be informed and participate in decisions regarding themselves, to receive appropriate care and services within the capability/mandate of the home support program..."

Conflict of Interest?

From Yirong Qin's paper: "Based on the underlying philosophy of IF models successfully implemented in other jurisdictions, the use of the Individual Support Plan as a needs assessment tool was recommended. In the context of the IF model, case management generally consists of planning, assessment, service linkage, coordination and monitoring. The Rights Based Social Policy suggested case managers (planning facilitators) who are not linked directly to the funders or service providers were more suitable to be responsible for service planning, linkage, coordination and monitoring of both clients and services.

The second and equally important element is to devise support plans for the implementation of needs identified by individuals. Ideally, the personal planning of support needs and service funding and delivery should be separated in order to rule out conflict of interest. Third, a potential solution is to transfer the control over resources and purchasing power to individuals with disabilities in the form of individualized funding (Stainton, T. (2005). Empowerment and the architecture of rights based social policy. *Journal of Intellectual Disabilities: JOID*, 9(4), 289-298). Individualized funding refers to the provision of funds directly to individuals with disabilities. (Torjman, S. (1996). *Dollars for Services: a.k.a. Individualised Funding*. Ontario: Caledon Institute of Social Policy.)

The statement in the report brings up a very cogent question: why would the health authority's social workers, case workers and counselors be in "conflict of interest" with the citizens they are mandated to assist?

In and of itself, this statement is even more evidence that health authority systems can find themselves at odds with the citizens to such an extent academic research is questioning whether employees in a government bureaucracy are more concerned with the bottom line of their health corporation entity and job security than they are with the long-term disabled in their own province.

Justify Results

When we talk amongst ourselves, disabled individuals, our friends and families challenge RHAs to justify the tasks they carry out on a daily basis. What are they doing to help the outcomes in the lives of other citizens? As they obviously aren't private workers, they are not building, manufacturing or ac-

tually contributing anything concrete to the GDP. Do they know this simple reality of economics? What have they improved or established to increase the long-term possibilities for disabled individuals in Newfoundland and Labrador? To open up more possibilities for citizens and the economy? What value have they created? Could they even justify their positive impact in a sentence, given the dire realities pointed out by ministers and deputy ministers of Health and Community Services that would suggest the citizens of the province are not getting value for their tax dollar?

"...disabled individuals, our friends and families challenge RHAs to justify the tasks they carry out on a daily basis. What are they doing to help the outcomes in the lives of other citizens? As they obviously aren't private workers, they are not building, manufacturing or actually contributing anything concrete to the GDP..."

Documentation says RHAs maintain responsibility for monitoring service plans and client outcomes. *However, this is what they are supposed to do, not actually what they do or even can do.* People who got on like that in my hometown were referred to as bullshitters.

Government provides some context to this in its own recent publications. In The Way Forward document, government identifies the tendency of some departments, divisions and authorities to disregard advice, ignore communications and operate outside the integrated framework necessary to adapt and improve programming. The government uses the word Silos to describe the insular groups contributing to gridlock and program failure.

From experience I have come to regard most of the statements by regional health authorities as being only words for cover, constant spin and crisis management to distract from the reality the system has long been unmanageable. *One would call it lip service, but there is far more lip than there is any kind of service.*

Not So Great Expectations

The suggestion is that all policies, programs and services should be guided by the following principles: accessibility, accountability, community inclusion, comprehensive selfness, fairness, flexibility, individualization, portability, transparency, determination and universality. Revolving around rights of individuals with disabilities, the rights of choosing locations to live, work and study are ensured by the principle of community inclusion; the right to require any accommodation or supports to gain access to programs and services is ensured by delivering programs and services in a fair manner which is free from bias or discrimination. Individuals' rights to control and direct decisions about their own lives and disability supports are ensured by the principle of self-related determination.

Even the premier admitted to me personally during a phone call 2017 our representatives don't know what's going on. In fact, the way he presented it to me is they just don't have the time to pay any attention to the real stories on the real ground level. That's not good. What else are you there for? We did

better 25 years ago. And why is that now?

The reason you don't know is because you don't ask. Perhaps the political party fundraising dinners could be replaced with visits to disabled individuals in your riding. Just saying. That's something like a 12-year-old would be able to come up with, let alone political parties with their high-priced communication support.

Missed Opportunities

Government and the regional health authorities are in an ideal position to provide services where they have greater purchasing power. This is already obvious in any proposal made for provincial, regional or national pharmacare programs. Instead, disabled homeowners who live \$10,000 below the poverty level have no option but provide services on their own with no access to available support.

It is obvious that in most areas the province, health authorities and government should be able to cost effectively co-ordinate public resources they avail of on a daily basis and provide for low-income long-term disabled homeowners the services of snow clearing, landscaping, most home maintenance and home office administration for a very small cost to the system, factored into the IF funding structure.

It would seem obvious to make the sharing of underutilized resources and the ability to offer general household assistance a part of the overall strategy. Common developments in mobile applications for mobile devices such as phones, tablets and laptops would be an obvious extension of this idea. An app for devices that allows departments and individuals to offer their services to qualified disabled homeowners seems only common sense. It would be straightforward to even get the software donated, as it is not a complicated peer-to-peer concept.

The joke among disabled homeowners is that Eastern Health will provide homecare, but not provide support to sustain a home to live in, forcing the individual into some sort of institutional care, perhaps into the residential style care the government has announced it is investing into expanding.

I have been told by those in the system that in these cases, the health authority doesn't have to see the cost come off their Community Support budget, and can then turn the file over to the institution where it doesn't impact upon that bottom line.

No Reporters

The obvious question is: who has invested in those pseudo-institutional properties? How close are the connections between wealth, political influence and the regional health authorities in the acquisition and profit from residential facilities? If there is a well-resourced news media, there is time to research these issues. By any professional evaluation, we don't have that now.

In 2016, Premier Dwight Ball faced heavy criticism for his company's receipt of two forgivable loans totaling \$800,000

to create 20 long-term housing units in his hometown of Deer Lake. However, it was the only story of its type covered. The public was told there's no conflict of interest in the Jade Holdings issue. As a long-time observer of Newfoundland politics, history and business, if a wealthy insider of the level of the premier is drawn into question, it is highly unlikely he would be the only one engaged in this type of situation. This behaviour doesn't occur in a vacuum. It isn't safe to assume every individual would be operating within conflict-of-interest standards.

Inclusivity

When one views outcomes through the frame of current institutional policy regarding inclusivity, we see our prime minister standing in front of crowds saying we should view inclusivity in Canada as being about finding and celebrating the value of everybody, including those on the margins. Everyone should have the tools and the opportunities, Mr. Trudeau said. One would think it obvious RHAs would want to hear input from disabled individuals with applicable skill sets. In a world of networking and communication and expertise, one would think. But that would be the smart decision and smart decisions do not seem to be a characteristic of the regional health boards.

The joke among disabled homeowners is that Eastern Health will provide homecare, but not provide support to sustain a home to live in, forcing the individual into some sort of institutional care, perhaps into the residential style care the government has announced it is investing into expanding. I have been told by those in the system that in these cases, the health authority doesn't have to see the cost come off their Community Support budget, and can then turn the file over to the institution where it doesn't impact upon that bottom line.

The Quebec welfare system provides basic income support. *I heard a commentator report on CBC News Network that in Newfoundland and Labrador, every time oil goes up \$0.50, our coffers get half a million dollars.* That's more than enough to cover me out for the rest of my life. *The gap between the wealthy and the disenfranchised continues to widen as the welfare state as it was created after World War II is being deconstructed. Are the marginalized disabled in Newfoundland and Labrador paying to protect the profit margins of the rich while they preach austerity to the taxpayer?*

Higher Standard

Government has indicated the most notable change in the healthcare system will be "that more services delivered in the community through new primary health-care teams comprising a broad spectrum of health professionals."

At this current time I know of no provincial standards or a focused code of conduct beyond the operational manuals referenced earlier to force the health professionals involved in the delivery of the service to think for themselves or take on constructive responsibilities in the delivery of home support programming. Individuals continually rise to the level of their own incompetence, known as the Peter Principle. The RHAs exist in an environment that is practically screaming out for some sort of quality management system.

An inability to think outside the box and the absence of a

learning culture or solution-driven workplace contributes to the atrophy that has led to an anachronistic system which is not meeting the needs of its clients or operating in a financially-sound matter.

In the nearly 15 years of interaction with the regional health authority Eastern Health, their behaviour toward me has ranged from inactivity, to arrogance, ignorance, envy of my education, conceit and condescension.

It's irrelevant whether or not I was consulted in the development of an individualized funding system, but they failed to speak with anyone even resembling a person with a professional understanding of management, disability and client experience.

Speaking Out

Here is a statement from the Deloitte report referencing advocacy: "first, by recognizing independent personal representation in law, not only are individuals with disabilities encouraged to develop self-managing health advocacy skills, but the option to choose care, services, financial and legal affairs through representatives is also available."

I've been showing my level of autonomous decision making since long before I ran into my first social worker. My experience with the regional health authority has consistently been:

As recently as 2017, I spoke directly to two representatives of the RHA, explaining in detail my situation, and although they listened politely, they showed no willingness to take any action. They did say, however in very glowing tones, "I was my own best advocate." One wonders how much taxpayers are on the hook for this painful insight into the obvious.

to those people everything is an obstacle. To these hapless fools, disabled people are out and out problems. To a hammer, every issue is a nail. I once asked a social worker "hero" what he knew about assistive technology programs for disabled individuals. His direct response was to complain he didn't have a new computer in his office. I kid you not. That is what he said.

The one I have now, when you try to approach policy issues or disability community concerns, her reaction is to make a low guttural groan, kind of sounds like "uuuhnnnnh." Honest to God. I only call these people when absolutely necessary. Years go by between calls. The experience of having to go to them repulses me. Their eagerness to diminish and downgrade everything one says is a dehumanizing experience. It really isn't positive for anyone's self-esteem to have to be exposed to this type of "authority figure."

It is a fraudulent hypocrisy that on one hand the system should be couching itself in such grand language while neglecting their clients and standing by while they suffer.

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Guided by Hypocrites

When the author of this report used his satire and writing skills to criticize Eastern Health in May of 2016, their vapid, arrogant, ignorant response was to send the police to the author's home under the guise of "seeing if he was okay."

(<https://www.saltwire.com/newfoundland-labrador/news/local/clareville-man-demands-public-apology-from-eastern-health-25187/>)

You see, I suggested to the client relations department of Eastern Health that there were ways of taking funds that were clawed back from those on the margins, back from those on the upper levels, \$50 at a time. If it was my brother in a wheelchair, that's the route I'd be taking. Yeah, that's called dark humour. Common technique in centuries of comedy and satire, still popular on talk shows and stand-up routines.

A pioneer of modern English language satire, the English journalist Jonathan Swift, suggested in *A Modest Proposal* in 1729, that a way to address Irish poverty was by the land-owners fattening and eating the children of the poor.

I've been using satire since I started my career back in the 80s, I was specifically hired by Newfoundland and Labrador's community newspaper chain to write satire, but the individuals responsible for sending the police to my home should have

known from my profile I was a writer who regularly takes shots at authority. They didn't. I made the mistake of not qualifying my comment (like I would to an individual with less background than an elementary school child) to an organization completely and obviously disinterested in me as an individual and client. Unfortunately, I already realize Eastern Health is shot through and through with selfish dull-

ards and I am well aware a cynical lack of depth combined with power over vulnerable individuals is a dangerous cocktail.

This is another situation where technology available 20 years ago could've prevented an unnecessarily aggressive unilateral action on the part of the RHA and saved the taxpayer the cost of sending the police on a Fool's Errand.

For my sarcastic broadside Eastern Health called the police. They made the fraudulent statement to the police they worried I was going to do harm to myself. I have serious secondary progressive multiple sclerosis. I am physically unable to harm myself. They didn't know that either? They knew my address, but they didn't know my phone number or how to contact me through social media?

Eastern Health appears willing to tell any lie to shut me up, because as a matter of course I'm telling the truth and exposing them for their continuing incompetence. The organization tasked with protecting our health, identified publicly by government as a failing Institution, instead of attempting to contact me, struck out blindly in an attempt to harm me. The idea I pose any threat is laughable. It's obvious who the threat is: ill-informed and poorly-led employees of the regional health authority Eastern Health.

We don't know the name of the individuals who made the call, lied and gas-lit me. It wasn't the mild gaslighting

spoken about by the former minister of finance of Newfoundland Labrador when he complained publicly about bullying in politics, it was a full-on attempt to destroy the reputation of a vulnerable, disabled person by a publicly-funded organization mandated to protect citizens of the province.

My family needs to know. *If anyone reading this document knows, please contact the author. It would be an opportunity to stand up to bullies who waste millions of your tax dollars.*

Of course I repeatedly asked for an apology and even appeared in a story about it in my region's newspaper, but the organization with many dozens on the Sunshine List would not even show enough civilized tact to reply to a homecare agency's cash cow.

Then-government minister Gamblin-Walsh, the focus of stories in the media where she draws attention to her own experiences with feeling marginalized, was another one of the public employees notified of my troubles with the RHA who did not even contact me to offer assistance or solutions.

As suggested by the Convention on the Rights of Persons with Disabilities, "instead of being an inherent trait of individuals with disabilities, communication incapacity is likely due to the lack of support from the social and physical environment."

In the era of "listening to everybody's story and having respect," the glaring fact disabled clients are not being heard or listened to and worse being gas-lit and attempting to be shamed by public servants is beyond cruel for these citizens, some of who are in imminent danger of having to leave their homes and go into some type of institutional care because they can't afford to pay basic bills. What kind of outcome is that?

Conclusion

The evidence continues to mount that RHAs are in great part responsible for the problems that exist within the system right now and will be the largest obstacle preventing the success of any future programming involving supports and outcomes.

The Deloitte report does not discuss if standardization will have any impact on outcomes for 24-hour care clients. Will RHAs still continue to support long-term disabled homeowners by offering 24-hour Home Care support? It begs the question: does this run contrary to the concept maintained by government and the RHA that client should be kept in their homes rather than institutions?

Even the mere suggestion that the regional health authorities could be trusted to ensure positive outcomes in the lives of disabled individuals is frankly ridiculous. They have a proven track record of underachievement and exhibit all the worst elements of the bureaucratic silos criticized by government in its own documentation.

Newfoundland and Labrador deserves The Whiz Kids, not The Underachievers. And believe you me, this bunch is dense.

And what's on the go with that now? Is it still acceptable to point out ineptitude and failure, or has it got to the point where they're more concerned about offending the feelings of half-wits wasting our money than they are with the quality of life of their most vulnerable "clients?"

Part 3

Homecare Agency Reality

Introduction

As this report shows, worsening negligent behaviour is being demonstrated by homecare agency management. This report will detail repeated failures to follow the Operational Standards Manual. The RHAs have no control and show little understanding or knowledge of their own mandate. *The Deloitte review references a lack of useful data from homecare agencies and the RHAs concerning their programming.*

Improved outcomes for the disabled appears to be an over-reach. From the government documentation combined with the research and observations included in this report, it appears as if promises are made by the government but are expected to be carried out by the regional health authorities who fund the homecare agencies.

The RHAs are presented as the linkage between theory and delivery.

Personally, I have been a client of government services for more than two decades and have used the services of a home-

Is it still acceptable to point out ineptitude and failure, or has it got to the point where they're more concerned about offending the feelings of halfwits wasting our money than they are with the quality of life of their most vulnerable "clients?"

care agency for over a decade. I have had multiple sclerosis for 25 years. My experience in management goes back to the 1980s. In 2016, I received a lifetime achievement award from the community where I live. So that is who I am.

From the Deloitte report: "consultations with program stakeholders revealed: *Concerns on the quality and variability of service quality; Concerns on the willingness of home support agencies to provide and fund training; An inability for the Program to be responsive to client needs through matching home support worker (HSW) skills and competencies to the complexity of care requirements; and, A lack of a defined career progression in the provision of home supports and incentives to seek higher salaries in residential settings. To compound these challenges, it can be difficult for home support agencies, particularly those in rural communities, to provide HSW with full-time hours.*"

The RHA have positioned the agencies as a completely reactive entity. They have not developed effective communications or technology transfer initiatives with the agencies.

Due to this, the agencies in my experience either do not understand or have rejected the policy of respecting the goals or desired outcomes for their clients and certainly have not evolved to a professional and technical support level where they could interface with individualized funding programming. At this point, organizationally, they represent a serious disaster and public relations nightmare waiting to happen.

Incompetent Leadership

There is also at this current time no structure for leadership or team development within homecare agencies, as the most pressing responsibility at the exclusion of ALL others, is to make sure "hours are covered off," getting their personal care workers to the clients on time.

I am currently subject to the organizational wherewithal of the Keystone Cops. The most revealing story related to me recently regarded concerns about the safety of a caseworker who was constantly on the phone while at the vehicle of their automobile.

Problems with homecare agency management had reached such a level by 2020-21 I was in a continual fear for my personal welfare and property. Never the workers per se, always management failure behind problems. I am with a new agency now, but they still face the challenges of being underresourced, overworked and without the capabilities to implement the progressive changes suggested in the Deloitte review.

In recent years it has become increasingly difficult for any agency handling homecare to cover shifts when regular staff are unable to work due to unexpected illness or requested time off for other commitments, such as family events.

Instead of paying any heed to the direction of the Deloitte Report and/or the Operational Standards Manual for the program, management will have to throw anyone in any client's home with absolutely no planning or consideration, as long as they can bill the government for the hours.

For the first half decade of my service, the agency who had my account maintained a pool of part-time employees. A few years ago, agency management gave me the excuse they were unable to find individuals interested in casual shifts, but I know this was a lie, as I'm aware of individuals who expressed interest and of a stack of ignored resumes on the desk of a certain case manager. *The reality is ownership is refusing to spend resources on employees or technical support resources, preferring to take the taxpayers' money they are funded for administration as profit.* I have overheard from good sources the management sees their work as "making money for Phyllis," who is the absentee sole owner of the largest homecare agency in the Trinity Bay area of Newfoundland and Labrador, located in Yorkton, Saskatchewan, with over 500 clients and less than four case officers to provide services.

Not only does this scenario cause uncertainty for clients, but also creates tension between employer and employee when staff are pressed into covering their coworkers' shifts.

What is required in this situation is clearly a job position for a "full-time casual," who would specialize on covering shifts at short notice. It would be wise for the agencies, RHAs, labour and government to quickly address this important issue swiftly, as a solution is easily available. *The Deloitte report suggests the development of a paraprofessional designation, which could efficiently address the critical situation with the lack of*

casual worker availability.

In my case, having to get shifts covered often put the caseworker in a difficult situation almost bordering on desperation. Caseworkers from the first two agencies to handle my homecare were reduced to asking their own employees if they knew of anybody who wanted to work a shift.

This is obviously unacceptable, but far from the only administrative failure by homecare agencies.

The agency who delivered my service until early in 2021 has boasted it now has 500 clients and 300 front-line employees, but they are backed by only two case management staff and are basically on their own, using human resource management techniques that have more in common with 1989 than 2019. It is to the benefit and credit of the caseworkers and agency employees they are utilizing SMS and Facebook Messenger.

Their hiring strategy is limited to the Federal job board, which is a recipe for chaos in the medical support industry. The lack of effort spent matching workers with clients and training and preparing them is having appalling effects on the most vulnerable.

In my case, I am treated somewhat like a farm animal. Ownership of the agencies appears to consider the quality of life of the client to be an afterthought.

Instead of paying any heed to the direction of the Deloitte Report and/or the Operational Standards Manual for the program, management will have to throw anyone in any client's home with absolutely no planning or consideration, as long as they can bill the government for the hours.

There was often a complete absence of information given to new homecare workers, who would often show up totally unaware of the client or environment.

Ownership, instead of implementing a hiring solution and adequate data transfer to their workers, exists in a continual state of panic where they are asking their own workers if they know for anyone who wants to come to work.

Recently, a case manager who left a dysfunctional agency started calling her former coworkers to let them know about the new agency. You can't make this stuff up.

Managers often had no idea who was working in my home at any time, and after a quarter century of the computer programs being available to make this an easier task, the agency refused to make any investments in helping its workers and clients, the most vulnerable in our society. This systemic failure has adverse effects for all involved except ownership.

The new agency I have been with this year uses an Internet-based software package for its scheduling and tracking, but the software has limited flexibility and only operates effectively with a four week rolling schedule, allowing employees to know their time off up to 28 days in advance, so amongst themselves they can cover off many unexpected irregularities.

Homecare agency ownership receives \$10 and \$20 per hour for administrative purposes. In the case of 24 hour care, in a decade the owner stands to make nearly three quarters a million from the household of one individual.

Our family wonders where all the money went. For a decade my service was handled by the largest agency in our region, a sole ownership of one individual in Saskatchewan. The management of the service being provided in the house left to me by our parents was woefully negligent. No resources appear to have been spent on technical equipment, necessary caseworkers, training, hiring or any form of professional development or sensitivity training.

Another great irony, is the agency then providing my services had a representative on the Deloitte Report's Stakeholders Advisory Group. A person who was working there told me there was some sort of system that was supposed to be implemented, but the boxes or binders or whatever went up on the shelf and were never used. So, that raises more than one question about the quality of that process.

The lack of professional standards and understanding creates obstacles to any government promise of improved outcomes, or increase the quality of team supports.

It became common with my previous agency for new workers to show up at my house, and not even know what medical condition I have. A couple years ago I wasn't given the replacement worker's correct name!

Client matching is an afterthought because as a homecare agency acquires a new client, it does not have a guaranteed pool of workers to draw from, as the agency has repeatedly demonstrated it cares only of profits and has neither a hiring or training strategy. The agency has to start from scratch, advertise with Employment Canada and cross their fingers.

The worker had home support training from a private college which indicated they could use a patient lift, however when I inquired they had been shown how to use the lift in a hospital, which is completely different. They were not trained with this lift, they were only shown how it worked. The private college had no on-site demo facilities for properly instructing individuals...

Clients are fortunate even to get enough workers to cover off their clients. As related earlier, the head caseworker at the agency whose services I now use has been trying to headhunt employees of her former agency.

Conditions with agency structure have continued to worsen over the last 36 months.

I experienced a situation where yet again a replacement homecare worker was sent into my home on short notice with no prior understanding of who I was or what the needs were. No experience using the lift and sling system that is essential to move me from my wheelchair to my bed or my wheelchair to the commode.

The worker had home support training from a private college which indicated they could use a patient lift, however when I inquired they had been shown how to use the lift in a hospital, which is completely different. *They were not trained with this lift, they were only shown how it worked.* The private college had no on-site demo facilities for properly instructing individuals to successfully complete home support tasks.

Fortunately, another worker who happened to be at my home was able to give a quick run through. I did my best to explain the parameters of the responsibilities and what is necessary during an overnight shift in the little time I had.

The agency doesn't pay me to train employees, but I do and have kept my mouth shut because I am afraid of losing my homecare service. I wouldn't trust agency management as far as I could throw them. not because I don't like them or they can't do their work, but if ownership or the RHA snap their fingers they would be forced to suspend my service.

I work well with my personal support staff, but due to nonexistent preparation, data or coordination on the administrative side, agencies continue to set a dangerous precedent by not being able to provide adequate information to their employees.

Alarming incompetence was shown by my previous agency in 2020, when after three months notice from a long-term employee they were going to leave to pursue their education, administration of my previous agency had made no attempt to find an adequate replacement. In fact, they had made no attempt whatsoever to hire anyone.

This deteriorated into a scenario I can only describe as surreal, when two administrators of the agency called me one afternoon, and in boisterously cheery tones, as if inebriated, boasted to me they had found this young fellow to come in as a replacement, the direct quotation was: "he's so good we wants to adopt him..."

The poor boy, when he showed up for a quick shadow training session, which is all the agencies will now provide, was a terrible fit for my household. I'd been a client, making money for this agency hand over fist for a decade, keeping to myself, totally self-sufficient and they acted as if they either didn't know or as if they were trying to make my life difficult.

It got worse. When the kid showed up for his shift, he had no idea he was going to be here by himself. *They either hadn't told him or they had lied.* The poor fellow was in a state, fortunately the long-term homecare worker who wasn't on shift that day generously came in and took care of his tasks. The poor boy was ashamed and on the verge of tears. We never saw him again.

If you thought it couldn't get even worse, you're wrong. The next person they managed to find a few days later was also a terrible match for my home and they should've known better. But in this case, the person wasn't even going to come in after the shadow training session, because they had a very poor memory and couldn't recall directions. *My family saw this as a red flag the agency might be able to shrug and drop my service at this point, with the excuse they couldn't accommodate me, which is one of their classic agency cop-outs known by all long-term disabled people in the province.*

With my back to the wall, with the help of some friends, I made a video for the person, *I actually made a training video so the individual would be able to come to work.* Fortunately, I taught at the college's journalism program for a couple of years (when it was Western Community College) and incidentally set

up the provincial college's first modern information office, so I had some skills in my back pocket. I wasn't paid anything for my work saving my ass from this woefully inadequate excuse for homecare management, and ownership are incidentally still pocketing taxpayers' money as you read this. And laughing at people like you and me who have to do real work.

The Last Straw

As my work on this report progressed, the blatant incompetence of agency management became increasingly glaring and in the estimate of my two older sisters, both retired health professionals, one in Newfoundland and the other in Scotland, they agreed management had lost any level of trustworthiness and it was best for my health if we avoid dealing with them as much as possible and start endeavouring to make meaningful changes before they committed anymore mistakes that bordered on criminal activity, given their decisions have had serious impacts on my health.

As the pandemic progressed, mismanagement of homecare service by my previous agency had descended to a point where I was filled with dread every time the phone rang.

I could self-manage my own care, but the homecare agencies are given more taxpayers' money to pay their homecare workers and have kept families out of the market as part of their scam.

During the most intense three-week lockdown in Spring 2020, my homecare workers had neither hand sanitizer nor masks. We didn't receive any until the Alert Level had dropped. Then, instead of sending a part-time or contract worker to drop off masks, for some unexplainable reason the case officer started driving around the whole region when they should have been in their office doing their job.

And during one of those visits to my home, this individual walked up to my wheelchair ramp railing wearing no mask and started to interrogate me about a recent post I had made on social media. I was totally mortified.

When the case officer showed up again a week later, I was in my backyard having a little fire in the firepit. The case officer walks up to me and blurts out: "you got it some good, don't you!" as if I wasn't a person with a long term disability living under the poverty level, the worst kind of blatantly inconsiderate judgmental, ableist criticism only the most thoughtless individual would allow themselves to say.

Two years ago, during some sort of staffing upheaval, I overheard in passing from a regular homecare worker that one of the case officers in the office (who incidentally I'd never met) had told so and so to do such and such because "Barry was mad..." What ever it was was so venal and foolish I can't even recall the topic. Most likely something childish.

I have substantially more intelligent and productive adult activities to occupy my time rather than tracking and reacting to the behaviour of immature, overemployed, publicly-funded individuals with little common sense or intellect who are preoccupied with reactive, finger-pointing more suited to junior high recess time.

This is the type of arrogant, ignorance which does much to damage the credibility and self-esteem of vulnerable people whose only mistake is to get caught up with case officers in over their heads who think they know everything and have no judgment or leadership skills.

This was so serious I was forced into calling their office and interrupting a meeting to clarify the situation. I hadn't said or done anything and it isn't the type of thing one of their employees should be making up off the top of their head in a blatant display of a lack of professionalism.

My caseworkers continued defaming me by telling prospective homecare workers that I am "particular" or "picky." This is the most horrible, ableist, cynical thing any individual can say about a person who is unable to move their body or use their hands to keep things away from their face or even kill insects.

Keep in mind, I have never been made a party to the reasons behind any of these accusations. I have never been shown the daily recording of my behaviour insisted upon by the RHA Eastern Health.

My family would certainly take legal action against these individuals, but we have been terrified into silence by privately owned companies and public servants, and because I have spent a decade developing a constructive relationship with my homecare workers in spite of the glaring, antisocial incompetence displayed by homecare agencies, I do not want to lose the modicum of comfort we have been able to create within the home left to me by my parents.

I could self-manage my own care, but the homecare agencies are given more taxpayers' money to pay their homecare workers and have kept families out of the market

tence displayed by homecare agencies, I do not want to lose the modicum of comfort we have been able to create within the home left to me by my parents.

But in weeks of the careless mismanagement mentioned above, I was forced into making a training video for the largest agency in our region in order to keep my service.

Underlying Technical Failures

The agencies commonly have no readily-available digital schedules or real-time profiling and in my case, the management of the previous agency nearly always had to call to see who was on shift.

The case manager didn't even know our senior homecare worker's phone number, and frequently had to call here late in the evening to find out.

The agency had worked with me for a decade.

Agencies should be legislated implement a standardized employee management software across the province, whether purchased or created locally. Recent critical failures in government information technology security raise questions as to the ability of government employees to create a reliable system.

Along with real-time scheduling, software must include customizable task list flowchart, as many currently use an off-the-shelf photocopy.

At my previous agency, a replacement worker was told: "they takes care of that themselves," when it comes to the hours and the schedule. Unbelievable. We were never compen-

sated for that.

Clients, workers and agency management need a standards/skills guide for both workers and management, based on simplified, portable versions of the existing Provincial Home Support Program Operational Standards. Section 3 outlines both Individual's and Worker's Rights and Privileges.

This would solidify specific parameters for the client/worker agency relationship for each client. There are certain work restrictions in the union agreement with the government that some prospective clients may not know, such as not being allowed to wash walls.

Prospective clients may not realize they are not receiving housekeeping services. Or, for example, a senior citizen who is used to working with an individual with some knowledge of food preparation may be matched with a worker who has trouble reading or understanding tools and or techniques, which can cause friction and lead to more time being spent by caseworkers in the agency finding remedies.

Lack of planning and coordination lead to hurried decisions that put workers in and client in incompatible situations. This can create tensions and toxic situations, leaving an understaffed agency management to spend time trying to "put out fires" by hurriedly substituting staff. These falling-domino scenarios are taxing to already overstretched services.

As shown multiple times in this report, these types of misunderstandings can be prevented by the RHAs if they actually had the oversight capabilities suggested at in the Deloitte report and attested to in the Operational Standards Guide. But they don't have that depth of capabilities or leadership skills.

Yet the agency administration keeps making the same sort of mistakes over and over again.

It must be understood that no savings will be found or improved outcomes guaranteed until the RHA provides agencies with a coordinated system that will allow for schedule, skills and outcome matching for clients. The support plan concept is impossible without this level and style of technology support.

Readily Available Technology

In the early 2000s, before receiving 24-hr care I managed two home support employees by myself, utilizing colour coding for schedules in an old Office 97 Suite and using other basic elements to track hours, etc.

The mid-90s Lotus Smart Suite introduced timeline tracking for small businesses available on desktop. We used that technology to help us bring Clarendville's Natural Media from a two-man promotions operation with a mom and pop print shop to the third largest printing and media organization in Newfoundland in 1999. As already related, I was on the Smart Communities team in the late 90s that developed a HealthNet proposal.

Given the provincial government has hired an outside consulting software firm to improve the province's healthcare system, it needs to be stated initiatives were proposed locally almost 25 years ago and roundly ignored by all levels of power in the province.

The agencies are missing a whole layer of enabling technol-

ogy that has been used for human resource management for well over a decade, technology utilization which is obviously the responsibility of the Department of Health and Community Services and the regional health authorities. This echoes a point made by other critics of the health system, who have identified lack of technology solutions in addressing waiting times for RHA services.

The urgent question is why didn't the RHA make any moves to introduce digital coordination solutions or quality management solutions? These solutions are common knowledge to anyone in private industry management.

...I was told by an agency source the RHA had informed homecare agencies they were instructed to tell their employees not to take any initiative over and above what any other employee is doing. Motivation, individualism and initiative are unlikely within this system.

One example is it would be relatively simple for the RHAs to implement a structure for sharing workers across home care agencies and the health authorities. Sadly, RHAs don't appear to have the intellectual or organizational grasp to be proactive in the field of home support.

The Level Playing Field

It is appreciated by clients that all employees must be compensated equally through the any collective bargaining agreement. This reality precludes having a structure where one personal care assistant could take responsibility for directing co-workers in the delivery of specific tasks on a client's long-term support plan. Lack of this structure is a chief factor in the failure of many homecare placements.

It would seem straightforward to suggest a supervisory level of personal care attendant, but that would carry a financial cost. When an individual takes a supervisory position over another, obviously there would have to be remunerative scale given greater responsibilities.

Given the imbalance in agency profits and the meagre amounts they appear to be spending on technology and delivery of services to the most vulnerable, legislation should be implemented to force home care agencies into creating supervisory roles and full-time casuals, as proposed above.

This lack of leadership structure has resulted in an environment where it seems likely that there would exist an inability for a client to develop any larger plan that is not directly supervised by them minute-to-minute in real time.

Four or five years ago I was told by an agency source the RHA had informed homecare agencies they were instructed to tell their employees not to take any initiative over and above what any other employee is doing. Motivation, individualism and initiative are unlikely within this system. Homecare workers are forbidden to do anything but the least amount possible, like management, yet, as we have seen they have been instructed to report back to head office about the behaviour of clients with no legal authority.

Without the complete downloading of the team support

concept to the client, their family and friends, the client's life would be in a state of complete inertia.

Another problem caused by inadequate matching of employees, is when personal care workers in a group with no direct supervisor have difficulty working together, there is reluctance to voice grievances and that can be a negative element that keeps individuals away from working in the personal care field.

Interruptions in service occur when workers quit suddenly, leaving agency staff to scramble. Employees are reluctant to complain for fear of further tensions or concerns about losing their jobs. Tension in the environment festers, leading to catastrophic breakdowns in service.

In properties that are directly managed by Eastern Health, the RHA has laid off complete in-house staff, leading to legal action on behalf of agencies. I've seen that myself.

The only way the promises can be kept will be if the RHA improves how they integrate information technology and how they transfer that technology to the agencies. *A standardization system for personal care workers skillsets and a process for matching skillsets with clients' needs is urgently required.*

Lack of RHA Initiative

It is interesting to read documentation on outcomes. It has been my observation that disabled individuals have long taken for granted that parties such as social workers, counselors and case managers are very concerned as not to stand up or do anything extra to stand out, lest they offend a co-worker, management or damage their social standing in the workplace. It brings to mind the often referenced image of entitled individuals leaning on shovel handles.

Unfortunately for clients, their friends, their family and society at large, the great majority of RHA employees that interface directly with us couldn't find an idea or initiative and put it into action to save their soul, but they can find an excuse in world-record time. If you could find mineral deposits at the pace they can find an excuse, we'd all be rich.

Simple Tools Available

Colour coding and digital tagging would offer a solution to an obvious hurdle to successful implementation of IF. Worker profiles could include areas of expertise and knowledge or interest, which could be matched to the needs of clients, who could specify area needs and their profiles.

This technology has been used online in my profession since the early 2000s, with the advent of online freelancing services, where providers are matched with clients.

In the private sector, it is natural for individuals to develop initiatives. This raises questions as to the value of the so-called private homecare agencies. Given the evidence I have noted, it would seem they are less private enterprises than personal companies designed to strip money from the health authorities for as little as possible effort or investment on behalf of ownership, which in my case didn't even live in the same province and appears to care little about how her "cash cows" live.

In this current economic climate, initiatives involving groups

and services integrate the development of applications for mobile devices. *Many possibilities for developing mobile IT solutions exist, and it is sad that the RHA do not take advantage of this technology to develop modules that will bring service and client closer together.* It is a shame the intellectual resources do not exist within the RHA to develop peer-to-peer crowdsourcing software to link volunteer individuals and organizations with individuals in need. It is an obvious solution that is being ignored.

Simple customizable flowcharts are another straightforward method to determine baseline list of necessities in any given setting. These can be augmented by a flexible interactive guide for both worker and client, where client and goals can

Unlike other important support professionals, there exists no obvious structure of standards and training for frontline personal care assistants...

...for a profession with so little industry support, the achievements of those in the homecare industry and their value to disabled citizens are incredible given the limitations.

be specified and task lists personalized, rather than shaping a standard photocopy to supposedly fit every situation.

To their credit, the new homecare agency I have been using for the better part of a year have adopted a cloud-based solution for their scheduling and logging. In its promotional material, it is presented as a complete solution for homecare environments, with the ability to manage all the data generated by workers and clients. Although the system has already demonstrated limitations in its ability to offer flexible shift lengths across different days and has failed to update its mobile device on occasion, software of its type can resolve most of the issues experienced in the majority of settings, but it has to be utilized properly and integrated as a part of the personal-care culture. Agencies must be held responsible for concurrent training in this technology.

My recent conversations with long time homecare professionals confirm that client worker mismatching is still a very problematic issue.

However, this type of software does not provide for profiles that would allow agencies to match clients with workers and that is a critical requirement, as the problem is costly and detrimental and desperately requires a solution.

Employee Retention and Attraction

As the personal care field is low-paying, has irregular, long hours with the possibility of stressful conditions and agencies refuse to reinvest their sizable profits on management and human resources capacity, a high level of employee turnover can be expected.

The extension of some benefits and the incremental rise in pay that resulted from the inclusion of homecare workers into a provincial union has somewhat improved the environment, but has been by no means a long-term solution.

Unlike other important support professionals, there exists no

obvious structure of standards and training for frontline personal care assistants. I've worked in the provincial college system as an instructor and information officer and for a profession with so little industry support, the achievements of those in the homecare industry and their value to disabled citizens are incredible given the limitations. It is a massive contribution.

It is sad to think that working citizens of Newfoundland and Labrador would be discouraged from taking initiative to provide value for the province. Why would an ambitious young person want to stay in such an industry?

Agencies must be legislated to re-invest a percentage of their profits into employee retention, training and professional development support resources.

Leadership Deficit in Homecare Delivery

There are pitfalls to the absence of leadership structure in homecare agency teams. It can lead to toxic environments where there is complete fear of taking the initiative, leading to tensions between workers and between workers and clients that can go unchecked until problems arise. There is paranoia about even being perceived to have done more or less than another employee. Total inertia is sometimes the best outcome. Simple misunderstandings can lead to catastrophic failures, resulting in clients who suffer because they have no coverage. The whole process of trying to find new workers or move the client is labour and resource intensive. These are self-created failures on behalf of the RHAs and the homecare agencies.

In situations such as mine, where I am on disability pension and have a marginal income, my only management recourse with the homecare agency is to lodge a formal complaint.

The agency system has no component for moving employees to better match clients. When a worker is assigned to a client they must stay there unless they leave by their own volition or are dismissed after a formal complaint.

A number of years ago, there was a situation where a worker was clearly not a good match in my household but an obvious good match in other scenarios, where the agency had already given them re-placement shifts. *After a series of emails and conversations, I was informed I had no choice but to deal with the individual or lodge a formal complaint.* I had ample issues with the individual that would warrant an official complaint, but as a former entrepreneur who has had some success as an employer, *it was very frustrating to realize a business in such a critical position of the healthcare industry had such a myopic and inflexible framework, especially when a collateral effect of the decision could potentially create discord in the work environment, which would at the very least take valuable agency resources to correct.*

At about that time, I received a visit from an agency employee who was serving as case manager at my home. *It was a quick visit and I was politely informed another agency client who was unable to get along with her homecare workers had just been dropped from that agency's client list. That was the entirety of the conversation and I interpreted it as a warning*

and a cautionary tale.

My disability and poverty leaves me exposed and powerless – I cannot afford to lose coverage. I vowed never to make any comments whatsoever to management. I've often noted that if their phone rings at the office, there's one thing I can guarantee them: it won't be me complaining about a worker.

Training and Standards Framework for Homecare

A training and standards framework needs to be introduced as readily as possible. Unlike other health fields, there has not been a training centre established. Only when there is a geographic and educational institution focus for the industry, can the field mature professionally.

The instruction given to workers by the agencies is in my experience, near nonexistent. To call it an afterthought would be giving too much credit. Although the new agency providing my services does give new employees some background information, the time allocated for training is woefully inadequate. Most commonly, the agency will now only give a new employee three or four hours to observe and learn their new working environment, mere hours before they have to take responsibility there alone.

Training Centre Needed

A training centre for home support/personal care specialists needs to be created immediately. Adoption of a standardized framework for workers in line with occupational standards and modern expectations for outcomes is a critical step to ensuring balance and consistency in the home support services provided to the most vulnerable in our province. It's also the most important factor in making the service predictably affordable and developing an environment of quality improvement.

At this time, training for personal support workers is an ad hoc mix of College of the North Atlantic's two-semester personal care attendant (PCA) program and an 18-week home

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support worker program sold by a private college. As far as my experiences go, we haven't seen many from the PCA program, as most go to higher-paying institutional settings. Recently, a graduate worked a couple of shifts in my home and was extremely professional, however it should be noted the individual is of exceptional personal character. One thing she told us about her training was both amusing and revealing: her instructor said the first time she would have to use a lift in a home support setting, the agency would provide a "nurse" to show her how to operate it. That's hilarious and reveals a total lack of understanding how the system is established and operates. This anecdote is a cautionary tale for how the private program operates: students are shown how

a hospital lift works. Are shown. *They don't actually operate a lift in a demo classroom situation as they have no demo classroom. The program is all about profit for the college ownership.* As well, the critical difference between the larger, more complicated hospital multipoint lift and the ubiquitous six point patient lift used in a home is not explained to students from the private college and they invariably show up here with no idea how to use the lift or the sling. These are incredibly dangerous scenarios the agencies and RHAs place the most vulnerable citizens of our province in every day and benefit financially from the process.

About a year ago, In an attempt to discover more about the nagging inconsistencies in the picture painted by the Deloitte review and the public relations approach of government/RHAs up alongside not only the realities of my life as a disabled person living under the poverty level, but also the first person observations of homecare workers and others in the system, I dusted off my old reporters' skills from the 90s and contacted the Department of Health and Community Services for an interview. It was unsurprising they refused, but they did "allow" me to submit a list of questions. The list of questions and answers is included in the Appendix of this report.

In the responses I received from the individual appearing to be in charge of the five-year plan outlined by the Deloitte review, Health Consultant Joanne Rose, MSW, RSW, she says: "The Department of Health and Community Services has established a working group to develop an educational strategy for home support workers in the province. The final report and recommendations are under development. Currently, there is a review underway to revise the post-secondary educational curriculum for the Home Support Program offered by public and private educational institutions in the province."

Obviously, that's more noncommittal, nonspecific government bureauspeak. Who is this "working group" and what are they being paid? Always have something "underway" and "under development" on their way to a new "strategy."

I'm looking forward to asking them if I can see the documentation they've so far developed, but I'm sure they'll refuse.

Unfortunately, dear friends, they are developing nothing but more gibberish and excuses. I didn't spend my whole life teaching at a college level, but I did work intensively as an instructor for two years and two more developing the promotions office for what was Western Community College on the west coast of Newfoundland.

Health and Community Services really didn't need to have any more meetings with their friends from other offices, which is basically the upshot of any process the department is involved with concerning this file.

The obvious initiative would have been to develop a central location with a standard curriculum, straightforward enough for for a course development specialist to put together in a compressed timeframe of no longer than six months. In the early 90s, I developed a series of course descriptions for a public relations/promotions module in the journalism program

that existed at Westviking College in Stephenville. That project came in at just under six weeks. I also observed firsthand the development of the Sound Technician program in Stephenville and was consulted numerous times during the process.

Even more unfortunately, the rapid problem-solving initiative necessary to set up a simple training centre is likely out of scope of today's public service and will not occur unless the issue is strongly forced.

The development of a training centre must be fast tracked by government. It is an immediate concern.

Overcoming a Deep Lack of Leadership

There are a wide range of learning styles among workers in the home support field, as in any profession, but among many new hires my homecare workers and I have noticed there is a pervasive attitude of dismissiveness, most embodied by lack of listening skills and interrupting when clients are speaking. My current agency had it mentioned to them by more than one worker. I suspect it's a learned behaviour, as an overbearing, arrogant tone almost consistently displayed by agency and RHA management frames the workplace environment.

There is a pervasive environment of institutionalized moral and ethical weakness surrounding those in charge.

An established home support specialist community with a training facility at its core would allow for the development of long term cornerstone policy across the industry. Centralized training built upon codes of ethics and practice for both workers and clients in the community support environment would take some of the insecurities out of hastily-assembled teams.

Readily-available digital profiles would allow for the movement of workers between clients within their own agencies, but also different provincial agencies and provincial regions with less downtime, helping improve outcomes across the system. Reducing the anonymity of the profession with awareness programs would make it a more attractive option for new recruits and those already within the system.

Personally, my experience with varying skill sets among workers is a direct reflection on the failure of homecare management to adequately match clients with workers or to under-

It is the responsibility of homecare agency management to ensure a functioning environment for their employees and the clients they are compensated for serving.

stand the concept of clients' and workers' rights.

It is the responsibility of homecare agency management to ensure a functioning environment for their employees and the clients they are compensated for serving.

Physically disabled adults in their own homes who are still highly competent and literate should not be placed with individuals hired "off the street" with no training or background who are more suited to work with the elderly or small children. *I have too often had to work with poorly-informed workers who seemed under the impression they were in a property owned by the RHA rather than a private residence and treated the home of a contributing citizen as if it was some sort of hospital*

or long term care facility.

It is common for "green" workers to not understand how to answer a phone and take a message for a client. Primary meal preparation skills are also foreign to a high proportion. I've been talked down to in ways that would make your skin crawl. Poor listening skills are common and I wish I had a dollar for every time I was interrupted while trying to politely speak.

It appears workers are adopting the arrogant, ignorant, know-it-all and dismissive attitude that is becoming pervasive amongst much agency management and the RHA.

As has been shown in this report, patchwork training and last-minute hiring also contributes to a toxic mix. *Many excellent people arrive in the homecare industry because the necessity for training is very low and individuals can start working and earning immediately. Those without post-secondary or secondary diplomas also find homecare to be one of few reasonably-paying options available in today's economy.*

Toxic Agency Influence

Individuals with little experience or preparation for interaction with a disabled person have a higher possibility of being involved in unpleasant situations with clients because they do not already know very basic cooking, cleaning and personal assistance techniques.

Workers with great potential and earning ability can leave due to stress or actions on behalf of the employer, usually due to environments that could have been prevented with a standardized nine-month training program. It would be also beneficial to train proven, versatile homecare employees to feel free to take initiative and be motivated to take on self-guided responsibilities. However, this last element may run into some opposition from those who believe a supervisory level needs to be introduced to the homecare union's bargaining unit.

Government states "agencies are subject to an annual quality audit process to assess compliance with the program policy standards."

Personally, in the years I have been a client of the RHA, I have only received one questionnaire from them. To send me a form regarding passing judgement on the homecare agency I work with would be counterintuitive because employees of the company would have had to help me assist in filling out a form that may have been critical of their employer.

Centre of Excellence Concept

Former deputy minister of Health and Community Services John Abbott referred to the desire to make the health system an environment for the development of centers of excellence, entities offering all levels of training and helping facilitate networking and coordination across the industry.

Personal support care would be an ideal area of health care for a center of excellence initiative. The public and private sectors already cooperate in the delivery of services for personal home support. They are in a position to take advantage of already existing technology and increase their efficiency by bringing together education, technology transfer and communi-

cations support in one location and provide help in facilitating a vibrant personal care community.

As stated above, training for a very basic set of skills would be of incalculable benefit to the homecare industry, clients, family and to the resource-stretched system. It would be a reasonably-fast solution to an endemic problem of employee turnover and dissatisfaction that is not getting better.

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Program development skills and unused government property, in an accessible location such as central Newfoundland already exist for a fairly quick development of a homecare workers' program under the auspices of the College of the North Atlantic, the RHAs, the homecare industry and the union. The private sector could also be involved.

The establishment of a center of excellence would increase the credibility and visibility of the profession and it would no longer exist in a vacuum. It would be an ideal location for certifications and extended professional development training.

I have worked in the development of centers of excellence initiatives during my time as an information officer and journalism instructor at Western Community College in Stephenville.

Finding Money

These are two examples of funding sources which may have been overlooked or not mentioned in the consultation discussions concerning IF in Newfoundland and Labrador:

Recent Federal/Provincial Agreement

The bilateral agreement with the federal government mentions home community care in the first sentence. From the media release:

"This agreement will improve access to home and community care and mental health and addictions services. It will support the province's priorities to develop a Home First Integrated Network, implement a province-wide palliative care approach, and enhance home care for persons with dementia. The agreement will also help create a system of integrated mental health services for children, youth and emerging adults, introduce e-mental health services in the province, improve access to addictions services and improve community-based mental health services. Through this agreement, Newfoundland and Labrador will invest approximately \$72 million in targeted federal funding..."

The stated goals of IF are directly in line with the areas presented in the text surrounding the agreement. The RHA and HCS should take initiative to pursue an element of this funding to direct towards improving the infrastructure of community support.

Agency Profits

The last, but far from the least important issue is the level of profits made by the privately owned enterprises that own

and run homecare agencies in Newfoundland and Labrador and whether the percentage of profits invested back into the agencies to support clients is even adequate.

Over and above the funding for salaries, my case officer at the agency I now use tells me homecare agencies receive between \$15 and \$20 per hour for every hour they work with a client. I wasn't able to locate the rate in any online searches, but my sources are reliable. Even at \$7.00, the rate homecare was compensated 15 years ago, a client with 24-hour care generated just north of \$60,000 per year.

In my case, I had been with one agency for a decade, meaning the profits were between \$600,000 and north of a million. From one home. As far as I know, no homecare business in this region spends any of their profit on information technology initiatives or giving back to their clients beyond a soup and sandwich get-together once a year.

In government's online registry of businesses in Newfoundland and Labrador, it indicates the agency which handled my services is owned by a single person. It didn't take much re-

...over and above the funding for salaries, my case officer at the agency I now use tells me homecare agencies receive between \$15 and \$20 per hour for every hour they work with a client.

search to find out that person does not live in this province, but in Saskatchewan, in a town named Yorkton.

I co-founded and served as executive editor of a company in Clarendville called Natural Media in the 90s. We took a mom and pop print shop and turned it into a responsive total media agency with on demand and offset printing. We were responsible for College of the North Atlantic's first distributed learning website. I'm aware companies have to move money around, to use successful areas to compensate for least successful efforts. These are measures that can be accounted for in a business's spending.

In 10 years of working with a 24-hour client, an agency now stands to take in \$1.5 million with no stipulation how they use this profit. This is absurd. The funding scheme for agencies should be examined by the RHA and Department of Health and Community Services to ensure inordinate amounts of money are not being taken by profits and a certain percentage is returned to invest in the agencies' infrastructure to support employees and clients.

The so most important question is what are they doing with \$17 per hour? These serious financial times call for serious measures and legislation could be developed to ensure if the agencies are not permitted to take inordinate amounts of money from a overburdened and broken system, making one individual or a small group of individuals inordinately wealthy due to a legislative oversight.

Conclusion

Part 3 shows again the RHAs and agency management create a serious chokepoint for the effective modern delivery of home support services as envisioned by the Deloitte review.

RHAs and the Department of Health and Community Services must integrate with the agencies in the Improvement of infrastructure and developing technology-enabled solutions to improve outcomes for clients and deliver high-quality services within budget.

With the colossal amount of profit received by agency ownership, the question must be asked why private homecare agencies have often complained they are stretched resource-wise, as in my case a previous agency had 300 clients and basically two job administrative positions to oversee all and support two caseworkers. A bookkeeper and receptionist, and that's it, using technology embarrassingly primitive by current standards, except for SMS and Facebook Messenger, which are utilized at the level of adolescent children. From my discussions with agency management, it appears as if Eastern Health seems to play no other role rather than financial assessment.

I'd spoken to an agency caseworker multiple times how they would be able to assist workers, the agency and the bottom line by including concepts of supercasuals or ringers to lower the stress caused by unexpected absences and utilisation of some very basic information technology strategies for promotions, retention and scheduling and software for coordination.

Although I was listened to politely, there was no indication any knowledge existed about technology transfer in the medical Industries and how it is currently relevant.

Reality for clients and agencies in the home support environment is "one makes do." Complain too loud and you risk losing your support. It is truly bizarre that in the 21st century, such a highly-paid group of individuals as richly-compensated agency ownership and the RHA administration should be offering what amounts to the legend of the Model T colour catalogue: any you want as long as it's the one we tell you is available.

Part 4

Regional Health Authority Reality

Introduction

During the community consultation session I was able to listen to during 2017, I heard a participant refer to their relationship with the regional health authority as "the continual run around." This observation concurs with mine. Eastern Health's premier characteristics from my perspective are ineptitude, evasiveness, obfuscation, neglect and unethical behaviour.

The most consistent theme in the first sections of this analysis is the shortcomings of the regional health authority, both on their own and in their inability to curb what are obviously common and concurrent infringements of the Operational Standards Manual for Support Programs.

To coin a phrase: "it ties the room together."

Born into Failure

When a previous provincial government proposed regional health board amalgamation, one of the promises made about the amalgamation was how much more effective and

resource-wise it was going to make us. Everybody knew it wouldn't do that, and the public came out and told government not to amalgamate the health boards. Amalgamation was a major topic of discussion in my region's newspaper, the *Pack-et*. In this case, the crows are coming home to roost.

It has worsened: in preparation for this report, I contacted my "social worker" during early spring 2019 to see if the person knew whether or not assessment forms would be issued that year. This is a very common document. As explained earlier, has to be done yearly. The "social worker" had no idea and passed the buck to the Financial Division individual who I've dealt with for years, who did not return either of the four phone calls I made to her office over two weeks. The paperwork showed up, but one would believe it their responsibility to let a disabled individual know, rather than leaving them in the lurch and creating toxic levels of stress and uncertainty in their lives.

As a final test, I started to discuss some agency failures, nothing specific, just to find out what this individual was made out of. As I spoke, instead of acknowledging what I was saying, this individual started making odd grunting noises, sounded like "ummuuuhh..." It was surreal. I felt like I opened a Pandora's Box full of morons. They kept asking me "do you want to launch a formal complaint?" I said no, I have excellent home care workers, and left it at that.

I asked if our conversation was under federal privacy and confidentiality rules. Not unless you're being harmed, they replied. And who is going to decide that, I wondered, this idiot? I wouldn't trust them to go to the store for me.

But Wait, It's Even Worse

During 2021, I attempted to obtain a replacement cushion for my wheelchair. Here's what happened: the "new" or "latest" occupational therapist (OT) informs me she has to make a trip to my home to measure the cushion. I've been using the same wheelchair for nearly two decades. I have already had three replacement cushions and the specifications are in my file. They have lost my file. Or destroyed it, or whatever they did.

Now get this: the OT had to be accompanied by a social worker for some reason to visit my home. When they arrived, the social worker stood in the middle of my kitchen staring out into space, didn't even have the common courtesy or respect to sit down when offered a chair, just stood there like an overbearing bigshot for 10 or 15 minutes.

The OT managed to measure the cushion with a carpenter's tape, but when the cushion itself showed up a month later, it was glaringly the wrong size, almost square, where my cushion is substantially longer than it is wide.

She had to visit my home a second time, and would you believe it, they repeated the same foolish charade where this social worker monkey from Eastern Health comes to my home and stands in my kitchen like some sort of hero.

And the taxpayers paid for her to be wandering around Clarendville like a child doing nothing.

And Even Worse Than That

The disappointing ineptitude and lack of coordination continued unabated. During the cushion fiasco, I also requested Eastern Health repair the six-point patient lift I need to get in and out of bed, etc. The castors, base and hand control were all in very hard shape after more than a decade of use, but all easily repairable. Eastern Health, however, preferred to bring a new replacement of the same model.

It was dropped off by a business they call "the vendor" and left in my kitchen. I contacted the OT and asked why they had not set it up, as it has a long, heavy boom and is obviously a two-person task. However, she assured me if there were any

...at \$7.00, the rate homecare was compensated 15 years ago, a client with 24-hour care generated just north of \$60,000 per year. In my case, I had been with one agency for a decade, meaning the profits were between \$600,000 and north of a million.

problems, all we had to do was call "the vendor" and they would "talk us through it." This wasn't the point.

The home support worker with me had just returned after having an operation, so there was no way I was asking them to do it. Fortunately, my agency caseworker happened to come by as this was unfolding and her friend was there to help out.

The whole process did not sit well with me and I wrote a letter to Eastern Health to let them know they should change this policy before somebody gets hurt and it blows up in their face.

After waiting two weeks to make sure I hadn't been sent a lemon by Eastern Health's "vendor," I contacted the OT to have them retrieve it, but it took over a month before anyone showed up. As it was seriously in the way in my kitchen and I was in the midst of training new home support workers during a transition to a new agency, the lift needed to be moved outdoors. Nobody at Eastern Health seemed to care.

A Shot In The Arm

When I contacted the social worker to request assistance registering for a vaccine, as I would require a home visit, all the worker would do was try to tell me about the irrelevant website I had all ready visited multiple times, very rushed and excited, apparently to get rid of me quickly as possible. I'm unaware what type of rubbish she was blurting out, but had had something to do with "I'll get the girls to set you up, then..."

This was typical bureaucratic gibberish, so I liberated myself from that "conversation" quickly as possible. I razed the social worker I was best doing all the work myself as usual and hung up. I went and called the main number and in a few days I was contacted with a date and time. How foolish was I, to think again that maybe the RHA had an intelligent, organized plan for disabled individuals during the pandemic. I must be the most gullible pushover in this province to think maybe someday somebody is going to show leadership and common sense.

Everybody Must Get Phoned

I also found it interesting how the Eastern Health crowd have set up their email auto reply when they are on vacation: one would assume your email to them is at least kept in their in-

box, but no, when they holiday you are digitally ignored. The onus is on you to call them again.

Eastern Health has a history of this type of obfuscation: soon after they were amalgamated into existence in 2005, many of their employees started changing the display that came up on our phones to "Unknown Name Unknown Number."

Breaking Up Is Hard To Do

Their uselessness reached its apex during a rather messy transition from my previous homecare agency, who over the period of a decade had managed to perfect the process of keeping me intimidated and taken care of in much the same manner an organization would take care of farm animals.

This difficult transition wouldn't have been necessary if families were given the same financial support for self-managed care as homecare agencies are given for providing the same

...I started saying in a very assertive tone about three or four feet away from the telephone receiver, "I'm not comfortable with you calling and speaking with workers like that, I find this a very threatening situation to be in," and honest to God, she was telling my homecare worker "I'm not being threatening..."

That's their attitude, like a high school bully saying "I'm not hitting you in the face" as they hit you in the face and their acolytes all laugh.

services. We would feel much safer at this point, given the record of incompetence, ableism and systemic failure, if we could manage the homecare ourselves. The system simply does not have enough intelligent or capable individuals in it.

After being contacted by the new agency, I invited them to make a pitch to my family, friends and I, as I was told they were looking to get clients and I knew their owner was previously the head of the provincial homecare agency owners' association. I was satisfied I would have a better chance of survival with them than the previous agency, which was run like a fast food outlet that didn't care if the food was edible.

Although the social worker tried to get me to call my old agency to say I was leaving, (even to ask a vulnerable, disabled individual to put themselves in a confrontational situation with persons in authority who have been already noted as abusive is inept), this wasn't going to happen.

She had to call up another one of the pseudo-civil service elite here and break the bad news.

The administration of my previous agency were under the impression that intimidation, poor communication and leaving workers in the lurch was an effective control mechanism to keep them under their thumb.

Not so with the good people who go over and above every day to provide the conditions of a somewhat normal life.

When the chief case manager at the old agency found out three workers were leaving en masse, and me, the goose that laid the million-dollar golden egg for Phyllis from Yorkton was leading the escape, she utterly lost it.

I happened to be in the same room when the case manager called and started to threaten the workers on the telephone!

I could even hear her when one of the crew was talking to her, trying to say that they wouldn't get any back vacation pay – I could hear her saying: "4% 8% 4% 8%" losing it and spewing lies left, right and centre, as we'd already extensively discussed the process with the new agency and signed off on it.

It was such a jarring experience for me I started saying in a very assertive tone about three or four feet away from the telephone receiver, "I'm not comfortable with you calling and speaking with workers like that, I find this a very threatening situation to be in," and honest to God, she was telling my homecare worker "I'm not being threatening..."

That's their attitude, like a high school bully saying "I'm not hitting you in the face" as they hit you in the face and their acolytes all laugh. Even writing this down, the recollection drives up my heart rate. What an amazing world I live in that it has such creatures in it.

The final part of this story concerns the telephone conversation I had with my "social worker" shortly after this experience. When I told this individual what had transpired and how it had made me feel, all they could say was along the lines of: "I don't know anything about that," and "I don't know what to say about that." They obviously weren't going to do anything

about it. The reality is the person was way in over their head and they didn't care.

The Chaos Engine

Eastern Health presents as a completely reactive organization. Its hiring focus appears to be the Peter Principle, ensuring individuals "rise to the level of their own incompetence," and its ranks are inflated with useless, irrelevant initiatives going nowhere, initiatives that should be halted immediately, because if they were in any way effective the Deloitte review never would have been necessary.

In more than one case, the individuals who continue to mismanage the health system were listed as stakeholders for both the Deloitte review and the Health Accord NL report. As another example: why was an office overseeing rural innovation allowed to exist while achieving nothing? It begs the question: where is the proactive oversight and the leadership to authoritatively prevent these disasters?

As we can see documented here, through more than a decade of observation and six different sections of this report, both the RHA Eastern Health and the majority of homecare agencies we deal with have managed to avoid investments in their employees and clients or doing any difficult professional level work by replacing what could be structured environments with complete chaos, led by overemployed, arrogant, ignorant and overbearing individuals who are most often completely in over their head when it comes to delivering any sort of acceptable modern standard of home supports. Keeping the most vulnerable and the poorest paid in an atmosphere of disorder, miscommunication, lack of understanding and lack of information is an incredibly powerful, intimidating tool for Eastern Health

employees and their friends in the homecare agency industry that don't want to see the money tap of taxpayers' funds turned off and certainly don't want to shoulder the responsibility for learning, intellectual behaviour and going over and above to help the most vulnerable. They are too lazy and too greedy and appear to operate in a dysfunctional parallel universe of entitlement that most of us wouldn't understand.

It seems unlikely these ill-informed individuals possess either the vocabulary, intellect or interest to even participate in information technology initiatives, let alone lead any.

Harsh as it may be, it has become obvious we are going to have to face these "drained brains" for what they are. If in the individuals can't be retrained, they must be replaced for the good of the people. It's not about being entitled to their entitlements anymore. RHA and the Department of Health and Community Services are primarily responsible for keeping the agencies in line, and they don't.

It should be common knowledge these type of information technology-based initiatives have long existed at legal facilities and other medical institutions in the private sector.

The assertion the home support system is making any progress with technology, especially Information Technology, is on a weak foundation, bordering on inane, childish fantasy.

Personally, I've made a habit of pitching in and leading from the front. I would challenge any of the people I've dealt with at agency management or the RHA to be half the citizen I am, half the citizen the great majority of these homecare workers are. I never saw either one of them middle managers stand up for anything but their own paycheque and little half-acre.

Deloitte Questions Current Standard

From the Deloitte Report: "currently, the operational standards define the provincial home support program's (PHSP's) following three goals: that individuals who meet program admission criteria have the support and services they need to live and develop fully and independently within the community in keeping with their assessed need; That individuals have choice in how they live; and, the program be equitable for all eligible population groups across the province.

The most far-reaching and long-term decision to solve the regional health authority problem would be the decentralization back to a smaller, leaner, sustainable group of boards more akin to the previous system.

To be able to clearly determine if these goals are being met would require systematic monitoring and reporting of key performance indicators for each of the three goals. This has not been the experience with the Program. The consultants did not find any key program indicators or an overall performance framework to guide implementation of the program or measure its performance.

There is a broad consensus that the Program is working well in terms of its primary goal but no ability to say exactly how or where it can improve outcomes. While most internal and external stakeholders believe the Program is meeting this

goal, there is no independent evidence to support this view. Others have raised the question as to whether these are the most appropriate goals for the Program at this stage of its development. As noted in Section 3.4.1, the results of the client satisfaction survey suggest that clients believe the Program help them live independently at home. There was limited data available to know to what extent other community supports and services are available to allow clients to engage with the broader community to support them in living independently. It is understood that clients assessed for their clinical needs albeit with some weaknesses in the current assessment..."

Deputy Minister

The former deputy minister of Health and Community Services, John Abbott, now as of autumn 2020, minister of Children, Seniors and Social Development and Minister Responsible for the Status of Persons with Disabilities has been quoted saying he believes improvements can be made through what he called a new "workforce management system."

"We just need to reorient our workforce to where we need them," he said.

According to Abbott, it's possible to shave several hundred million dollars from the health budget, however, up to the time this report was written, there were no specific details as to how this would be achieved.

Structural Change

I wouldn't be considered a follower of Canadian academic Jordan B. Peterson, I did find his quote about organizational structure informative: "One of the rules for making an organization is that it's a lot easier to make a functional organization worse than it is to make a dysfunctional organization better."

The most far-reaching and long-term decision to solve the regional health authority problem would be the decentralization back to a smaller, leaner, sustainable group of boards more akin to the previous system. The current structure is unwieldy and untenable because accepted initiatives, programs, attitudes and work ethics, as well as readily available information technology are not being adopted, because the actions of planning and administration have become too scattered and dif-

fuse. The leadership was never able to keep up. To coin military terminology: they are combat ineffective.

It must be kept in mind that when the current boards were formed, digital communication was a generation behind where we are now. Amalgamation of health boards now makes much less sense given this dynamic, and decentralization would eliminate resources being stretched across geographical areas and a large number and variety of clients. Behaviours would be far less likely to get out of control in any division or department stretched geographically and rife with multi-levels of middle management as is the case in the larger RHA structure.

As well as the obvious benefits of a streamlined organization, community-based board leadership would replace the current corporate model, where the two highest officials of Eastern Health receive three quarters of a million dollars per year

sitting behind a desk, positions the citizens of Newfoundland and Labrador can get at a far lower cost with an executive that isn't composed of high-priced corporate figureheads.

Government continues to insist they need to further amalgamate health boards and home support companies. This will be futile and cause serious damage to the lives of our people. The system's problem is not the system itself, rather it is the individuals in charge of it. To give these same people a larger system, when they can't handle the current one is a massive mistake and should be prevented.

Limited Options

In lieu of a structural change, there are limited options to improve the outcomes for disabled homeowners in system. The counterintuitive yearly financial assessments continue, albeit somewhat shorter, but now dependent on yearly tax returns and documentation from service providers, so still unnecessarily complicated. Complete implementation of One Access Point as proposed rather than just making it easier for the financial divisions of the regional health boards is critical.

I tried to give everyone the benefit of the doubt, but my new social worker at Eastern Health, who contacted me first on January 20, 2020, may be the most poorly-informed of any individual I have yet spoken with. The individual had no idea about my background whatsoever, even though the person had accompanied a previous social worker to my home multiple times. The individual had no idea about the IF changes. Had no idea I was tied to any controversy that had appeared in the media over the last 36 months in relation to my struggles with Eastern Health. This individual was oblivious to the issues important to every disability organization in the world today.

Ten Random Unforgettable RHA/Agency Experiences

These are the top 10. There are too many others to count. I had to cut the story of the crazy guy at Eastern Medical Supplies who freaked out at me because he had sent me the wrong replacement sling. Hoo boy. Not of this world. It has been necessary to take a flamethrower to many of these memories and I am fortunate to have developed the ability to compartmentalize.

10. An occupational therapist (OT) approached me and offered to spend \$20,000 of your money for a large, complicated electric wheelchair I could not use, because my driveway is to uneven, my deck old and my house too small. I can't understand why my occupational therapist tried to push this on me, before offering suggestions on how to get the deck repaired and doorways modified. The OT was so enthusiastic about showing me the chair and getting somebody to come in from the mainland with it, I started to wonder whether or not she was getting some sort of commission.

9. A few years ago there was a story on CBC television news about the complaint from a disabled man living in residential care in Quebec who wasn't able to have a daily shower. I laughed out loud at that. I literally can only afford to heat water for couple sponge baths a week, and I consider myself to be lucky to have that. And don't forget, the health authority was still expecting me to pay for hand sanitizer for home care agency employees and snowclearing for access to my house

for a full decade. If it hadn't been for Covid, I'd still be buying the sanitizer..

8. Back before I qualified for homecare, I often existed under what is known as the one-meal strategy. Sleep late as possible, wait as long as possible after waking, eat one meal, have a small snack before going to bed. Repeat. A variation is to have a small breakfast, wait as long as possible and have a meal an hour or two before bed. I got adapted to going to bed hungry 15 years ago after extended training in university residence.

7. I almost died from a vicious case of kidney stones in the summer of 2016, following a decision by my doctor to schedule a colonoscopy on my emaciated body 48 hours after having two stents placed in my bladder. Less than a day after the colonoscopy I started vomiting black bile and was taken into emergency at the G. B. Cross Hospital in Clarendville. After having my stomach pumped empty, I was told if my bladder and bowels didn't reengage after 24 hours, the surgeon would have to physically go into my bowels and there was only a 10% chance of my survival, given my emaciated state. When I was released from hospital, it was done so with the express instruction of doctors and staff to eat lots and gain weight! All I could do was smile at the poor people, they had no idea, they were government employees who had lived for so well for so long they had no concept a person in their community who had done everything expected of them their whole life might be going hungry, living \$10,000 below the poverty line, dependent upon food banks and the charity of strangers. In the light of that episode, any publicly-funded health authority public service announcements about self-care that reach my eyes or ears are taken as a joke.

6. There used to be an MS Clinic in Newfoundland. When Eastern Health was formed, they closed this clinic and combined all services under their neurology department. When I tried to keep my neurologist informed of some of the struggles I was having, a woman named Janet blocked my email address. On a phone call she said people with multiple sclerosis didn't use email. This was within two years of amalgamation.

5. The supervising counselor with Eastern Health once warned me bad things would happen if I was overly critical of middle management. As my father was a World War II veteran with the esteemed Newfoundland 59th Heavy Artillery, that did not go over particularly well. This Eastern Health hero tried to tell me namby-pamby wasn't a word. Orwell anyone? Cowardly, ill-informed bullies? My dad had every reason to stay out of World War II, but he made the decision to run with the big dogs instead of lying on the porch. This Eastern Health hero forbid another one of my former counselors, a weak-willed man, to speak with me outside of work for four years, a figure she appears to have invented.

4. Around the time of amalgamation a new social worker showed up and I had to sit and listen to sour grapes that the social work professors at MUN couldn't get tenure. When Eastern Health withheld foot care services, she stood in my living room with a short summer dress in open top shoes like she was on Sex and the City and informed me there was nothing

she could do.

3. In the mid-2000s, as my condition worsened and I needed more assistance, I contacted Eastern Health to get a commode and adjustable bed. A community health nurse visited and wrote some things in a clipboard folder with the words Eastern Health embroidered on the front in red. I specifically indicated my body size and shape, I received a short, narrow, primitive bed that looked like it came out of a World War II field hospital in the Soviet Union, a plastic pad the thickness of a hamburger serving as a mattress. It had a crank like a Model T. I couldn't lie on my side. It was a night of pure torture.

2. In 2015, it dawned on me that the electric lift I have been lent by Eastern Health was nearing a decade old. I wondered if there was any provision for replacing my lift on short notice. In 2012, a group of my university classmates created a fundraising trust, which assists me in purchasing essential equipment not covered by Eastern Health and they purchased a manual lift for me so I wouldn't be stuck during power outages and they also bought a secondhand lift so I can use the basement chairlift that was already in my home. I called up and asked the occupational therapist and they have no provision to cover the clients that need these lifts for basic human needs like going to bed and using the toilet. No emergency backups, when obtaining and organizing them would be ridiculously simple. I was able to obtain a secondhand electric lift in my community, and I have been told by some veteran homecare workers that there are many of these going unused in households that used them for an individual that has now been institutionalized or has passed away. I have sardonically joked they do that to drive people into respite care so someone is able to make a dollar off of it if you won't be able to come back to your home.

1. In about 2009, a co-owner of the homecare agency I was with who was supposed to be telling a homecare worker the hours when he was supposed to be doing a shift at my home, stood and jibber-jabbered at the individual who by all accounts jibber-jabbered back for 20 minutes, and neither one of them had a clue what the other one was saying. They managed to wind up leaving me in my bed alone for 21 hours. It was a horrifying, depersonalizing experience to say the least. I will never forget that or forget the multiple times I fell out of bed before I had complete homecare coverage.

Responsible for Anxiety

For individuals with disabilities, physical stress can be derived from inaccessible environments and unwieldy service delivery systems; social stress can be derived from discriminatory behaviours and social exclusion; psychological stress is likely to result from both the actual experiences with the former two sources and the mere anticipation of them. As demonstrated by the biopsychosocial model, medical, social and psychological factors not only interact with each other, but also feed into each other. The chronic stress derived from social conditions is likely to suppress an individual's immune system, and which in turn exacerbates their physical and mental illnesses and forms

a vicious cycle of distress. (World Health Organization WHO 2006)

This report has been able to prove the RHA model's failure is in large part responsible for the amount of stress transferred to these individuals or clients. *Eastern Health has abrogated its responsibility to the health agencies. No technology transfer. No information technology utilization.* The concept that I would have any direct control via a homecare agency is a dangerous untruth. In reality, this can't be promised. The regional health authorities don't even know how to help the homecare agencies on even the most elementary level.

Conclusion

The key to success with the implementation of individualized funding (IF), is changing the way the regional health authorities operate. I am suspicious about the system such as it is being capable of making effective, progressive innovations and improvements.

In 2004, the public of Newfoundland warned the government not to create amalgamated health boards. This is a simple fact.

Government did not listen, so are now ultimately responsible for having created in the health system administration and management a culture of **cognitive dissonance** (a state of having inconsistent thoughts, beliefs, or attitudes, especially as relating to behavioral decisions and attitude change) and **confirmation bias** (a tendency to attempt to interpret new evidence as confirmation of one's existing beliefs or theories) associated with the shortcomings of the RHA.

The concept that I would have any direct control via a homecare agency is a dangerous untruth. In reality, this can't be promised. The regional health authorities don't even know how to help the homecare agencies on even the most elementary level.

Throughout nearly two decades of existence, their whole horrific failures, from the cancer test debacle to an inability to clean scalpels have been well documented in the media. *The administration of the RHAs is gobbling up taxpayers' money at a rate unequaled proportionately in the country, and honest-to-god, some of them even think they are driving the economy. With somebody else's money.*

They reject violently the concept they should take personal responsibility for correcting these failures. These individuals are arrogant and ignorant to the level they do not even understand they are not creating or building or producing anything, they are only spending somebody else's money while driving their organization further into the ground.

As the American President Lincoln sardonically remarked about the hanger-on public servants of his time: "too many pigs for the teats." They're all trying to climb on the wagon. It can't cart all of them.

I've seen very few health board representatives for the better part of a decade, and even then they have done very, very little. Nothing that a piece of software couldn't have done. As we've seen in 2021, the health system can't handle main-

taining information technology resources, either, and the world witnessed in Newfoundland and Labrador a data breach caused by outside hackers. Sadly, I predicted this sort of thing as far back as the mid-90s, when another local fellow and I were operating the Atlantic region's first full-service media agency: the first couple of hires we saw in the public service in our area to manage information systems didn't have the skills to work in our shop.

Eastern Health's Community Support programming is plagued by ineptitude and poor leadership, a completely inadequate understanding of what it means to be disabled. More than 90% of the individuals I have been unfortunate enough to have to deal with for 15 years are besotted with self-entitlement issues, they are socially aspirational, and even more depressingly they are poorly-informed automatons with a pathetic lack of general and current events knowledge and even understanding of their own occupation.

The danger of having small-minded, unmotivated individuals with a low-minded lack of initiative holding these important roles is well known to history.

It's time to face harsh facts. These people have to be stopped or they will bankrupt us and leave with their pockets full and probably try to make themselves the victims. Ignore this at your peril.

If the legislation is not designed to fix this crown corporation version of a collapsed black hole, my warning is any well-meaning initiative (such as Health Accord NL) to realign health services to a transformed, socially-conscious horizon, will have failed before it even starts.

Final Conclusions

To my knowledge, this is the only examination and report of any kind about developments in the community support system and its programming in Newfoundland and Labrador.

To the best of my knowledge, I am the only disabled person in our province with a professional background in media, education, entrepreneurship and promotions to have done any writing on the subject.

I'm glad to have the opportunity to write this document. I was given no other opportunity to contribute to the discussion surrounding changes that will directly affect my life and I have never been given a serious opportunity to make a comment about the negative impact that Eastern Health has had on my health during the nearly two decades my disability and poverty has forced me into interaction with their organization and its representatives.

It's important to know the government's department of health and community services believes they are actually a stakeholder in the system rather than the individuals who are responsible for mis-managing it. Be it ignorance, arrogance or shameless and brazen gall, they eagerly took salaries of taxpayers' money, per diem's for food and mileage while watching the system crumble and contributing to its deterioration and direct damage to the health of Newfoundlanders and Labradorians.

It's also important to remember the very same groups who were part of the regional health board amalgamation in the early 2000s and were responsible for the early disasters including incorrect lab work and inability to keep medical equipment clean are the same groups who framed and defined the Deloitte review process and are now part of the Health Accord NL reports and program which is supposed to once again reframe and improve the health delivery system in the province.

Even a cursory glance of the stakeholders sections of the Deloitte document and the Health Accord document will reveal we have tasked the same inefficient, ineffective structure responsible for getting us in the mess we are in are the ones who are spending more of our money to boldly promise they are going to "fix it" again.

This report is a blunt and honest assessment of the individualized funding model for Newfoundland and Labrador and the chances of its successful implementation.

Although individualized funding is both a progressive and a common sense concept, this report demonstrates that its daily operation will depend on a health board system which is already proven to have serious problems and is unable to carry out its mandate even at the level of its predecessor organizations. During the general discussion part of the consultation session I listened into, a participant spoke about the stresses that come along with the broken system, she repeated "broken system" a couple of times.

If this important reality is not accepted and addressed, as this report shows the individualized funding model failed before

it even started.

Government, Deloitte and academic documentation on the individualized funding subject for Newfoundland and Labrador contains some very beguiling, fine and fancy language. Quite a bit to live up to.

Realities of Disability

My report has been informed by my personal experiences throughout more than a decade of disability and poverty. I have reached a point in my condition of multiple sclerosis where I am exhausted of homecare agencies throwing everything but the kitchen sink into my house and hoping the result would be a successful outcome rather than the self-perpetuating failure. I truly despise having to endure the risk and stress of trying to train and adapt individuals who do not have adequate listening or learning skills to carry out tasks to which they are neither suited to nor are capable of.

As I was finishing this report during November 2021, there

...I have compiled this information and written this report because nobody in Newfoundland media, academia or the medical system has written anything about the proposed changes to the provincial community home support programming.

was an overnight where my new agency, who are doing their best, had no choice but to send in a person who was not capable of either putting me into bed nor reliable with being able to respond to my needs when I was in my bedroom and they were in another room. Again, I have no criticisms of this individual, nor of the agency managers with whom I now work. However, I did not feel comfortable enough to go to bed that night, so I was forced by a systemic failure in the system to stay awake overnight. It isn't a big deal to me personally, I went to college in the 80s and partied hard in the 90s.

I shouldn't need to repeat to an organization full of self-declared and self-professed experts, (see the stakeholders section of the Deloitte review or the Health Accord Report NL) how critical enough sleep is to those who live with multiple sclerosis. I've had MS for nearly three decades.

Until legislation is enforced to make agency ownership invest in adequate casual support, that is the super casual or ringer or paraprofessional, what ever the term, individuals like myself will continue to be failed by agency owners while these people, some of whom do not even live in this province make unusually large profits comprised entirely of taxpayers' funds. Most abled individuals living everyday lives don't think about disability and its repercussions.

Only when their children, their parents or themselves become so marginalized by disability they have to live \$10,000 beneath the poverty level, go without a shower for months, cut back on food and rely on an inconsistent and undependable health authority, (while being told living at home is more affordable than institutionalization) are they able to understand the desperation.

I've done my best to stand up for myself. I don't scare easily. My struggles with the health board have been well documented in the region's newspaper. Friends and family have been there to assist with fundraising efforts to fill in the holes left by the system's failures. I've written extensively about my experiences. I've contacted all government representatives and even managed to get a quick discussion with a premier.

However, the quality of my life has not improved. Nobody in this system has lifted a finger to try and help me. On the contrary, they have threatened me and withheld services and funding. A former CBC journalist made an astute observation on Twitter a few years back when I posted a link to a story about Eastern Health's attempt to gaslight me: "nobody cares."

One doesn't get this kind of depth or context from a Deloitte report or a government media release. This report manages to connect the dots of reality with the presumptions and data from the government and its research agency.

Only when blindsided by serious disability is one able to fully appreciate how difficult the struggle is trying to maintain home, health and dignity.

I promise you one thing: I'm never going to parrot the talking points from the RHAs and the government.

I'm not the government-sanctioned advocate, because that's no advocate at all. That is just a sellout in waiting. Instantly compromised from the beginning. I'm not a board president or the chair of an advisory council. I'm not going to sit there and kiss anybody's ass.

I'm skeptical, suspicious and I don't believe authority without question due to its history of misinformation and malfeasance. As the son of the World War II generation, I believe the truth surrounding work ethic and sacrifice is self-evident.

I have compiled this information and written this report because nobody in Newfoundland media, academia or the medical system has written anything about the proposed changes to provincial community home support programming. The head of the nurses' union in the province said publicly in reply to my question during CBC Television's Critical Condition Forum during May 2018 that she didn't know anything about it.

The individualized funding proposals are backed by research and observation. Individualized funding and a single point of access are relevant ideas to implement provincially.

Review of Core Concepts

What is Individualized Funding?

Individualized Funding (IF) is a method of supports that is determined by an individual's need and is directed and controlled by the individual. It seeks to improve service by giving individuals the independence to identify their needs and choose their support providers. Individualized Funding is different from indirect funding, or supply-side financing, where funding is administered from government to a supplier or agency. Individualized funding means people decide on the supports they want and need so that they may plan their money accordingly.

Rights of Disabled individuals

Patients' self-determination, especially individuals with long-term or chronic conditions, started to become more pronounced in the 1980s due to an increasing emphasis on pa-

tients' informed-consent and preferences. The shared decision-making process instead combines professionals' technical knowledge with patients' preferences by information sharing and encouraging patients to become autonomous decision makers, which reduced the informational and power asymmetry between professionals and patients. (Charles, C., Gafni, A., & Whelan, T. (1997). Shared Decision-Making In The Medical Encounter: What Does It Mean? (or it Takes at Least Two to Tango). *Social Science & Medicine*, 44(5), 681-692).

Individuals with disabilities are consumers of services instead of victims of biomedical conditions. A new approach to service provision is to increasingly promote self consumers to codetermination and personal choice by advocating control over which services to access, to monitor the quality of service provision and to change services if necessary (Prince, M. J. (2009) *Absent Citizens: Disability Politics and Policy in Canada*. University of Toronto Press, Scholarly Publishing Division.)

According to T. Stainton in *Empowerment And The Architecture Of Rights Based Social Policy*, *Journal of Intellectual Disabilities: JOID*, 9(4), 289-298 (2005), Canadian disability policy and practice should progressively move away from the assumption that individuals with disabilities are incapable of making choices.

Support Planning

Based on the underlying philosophy of IF models successfully implemented in other jurisdictions, the use of the Individual Support Plan as a needs assessment tool was recommended. In the context of the IF model, case management generally consists of planning, assessment, service linkage, coordination and monitoring. The Rights-Based Social Policy suggested that case managers (planning facilitators) who are not linked directly to the funders or service providers were more suitable to be responsible for four elements: service planning, linkage, coordination and monitoring.

Process and Protocol

In order to implement the individualized funding solution effectively, government will need to swiftly cut through systemic obstacles eliminate the knots with a sharp blade.

The principle is that among competing hypotheses, the one with the fewest assumptions should be selected.

It isn't safe to assume it just because the government and RHAs say it. I've seen what happens in the real world, and what has been seen cannot be unseen.

CBC's Critical Condition Forum

On May 30th, 2018, CBC News' Here and Now program held a public consultation as a part of their Critical Condition series on the state of Newfoundland's health system. Doctors and Debbie Forward, then head of the nurses' union attended as expert sources. I had the opportunity to ask the panel about individualized funding and also if health services were better under the regional health authority system than they were under the previous arrangement. There were no takers for the first question, Debbie Forward said she did not know anything about the government's new individualized funding system, but candidly answered my second question by saying it depended on "who you ask and what day of the week it was."

She added government hadn't done adequate planning before it implemented the regional system in 2004 and due to that short-sightedness there are still serious negative repercussions in the way health services are delivered. That assessment from the province's senior nurse should give the people cause for concern.

No Quick Wins

In the Deloitte report, administration and bureaucracy are claiming (and assuming) they will achieve quick wins. In fact they even have a Quick Wins section. How presumptuous and cynical is that? Dr. Goebbels would be proud of them.

Their first "Win" is supposed to be the plan to implement the changes. Their second is supposed to be somebody actually starts the process. And the third "Win," is they write another report. Honest to God, that's on page 63 of the Deloitte report.

Any discerning reader is going to wonder if Deloitte has written a review or government propaganda, because government have obviously already decided they have a victory years before anyone even develops a plan, regardless of if the whole implementation process is the same kind of train wreck overseen by the regional health authorities throughout the last decade and a half.

Most likely the people who will be sitting around at the meetings are the very same group of individuals who are overburdening our system right now and pushing our government bureaucracy 10% higher than anywhere else in the country per capita, a ridiculous situation in a province with such a small population.

This whole phase is obviously only communications work plus more administrative and governance tasks. A Quick Win for whom? Most likely the people who will be sitting around at the meetings are the very same group of individuals who are overburdening our system right now and pushing our government bureaucracy 10% higher than anywhere else in the country per capita, a ridiculous situation in a province with such a small population. Is there any mechanism available to circumvent money-wasting self-serving communications effort such as Quick Wins?

Government and RHAs should be more concerned about making solid, meaningful decisions. Real wins rather than quick wins. From the perspective of a long-term disabled homeowner, the essential single point of access and team support needs to be backed by information technology, client service matching with personal home support associated services, inclusion of available existing government services and bringing home owner rights in line with renters.

I'm not a public servant so I don't have any personal reasons to be anything but critical of unnecessary errors within government departments and agencies. With a background in journalism, research, entrepreneurship and media management, I am duty-bound to be skeptical. We need to show the will in this province to align our government bureaucracy with the rest of the country and get these individuals off the government pay-

rolls immediately.

Financial Division Changes

It is going to be essential to realign the financial division as it impacts disabled individuals availing of community support. The concept of one point of access may be the only concrete move that can be made at this point.

Savings shouldn't be found on the front line, they have to be found in the back office.

As stated earlier, I've been trying to hold the financial divisions accountable for their waste and irrelevance for the better part of a decade and it was a major theme of the Stationary Hobo articles in 2016-17.

Public perception is that the regional health authorities division responsible for Community Support programming couldn't run a lemonade stand. They already can't look after themselves or the citizens they were hired to assist. They need to be reminded: be careful where you tread when you have somebody else's money in your pocket.

Client Services Changes

Deloitte reports that "Eastern Health regularly tracks and reports on a number of quality indicators that are used to assess Program performance in the region." I haven't seen that procedure happen. I was sent a questionnaire five years ago, but the only persons available to help me complete the forms were employees of the service they were asking me to make comments about.

It would've been preferable and simpler to have asked me personally, but as this report shows, it's more about the RHA and their excuses and propaganda than the quality of

life of disabled clients.

I find it ironic that government's associated health services are often the individuals we see interviewed or doing public service announcements, telling everybody how important it is to tell their stories and how critical it is for everyone else to listen to the stories, especially from those on the margins. By their own standards, their behaviour might make them the biggest hypocrites in the province. The hallmark of the abused as we have seen, is they are not listened to and believed.

This is a perfect reflection on how the RHA treated one disabled client, me. From the small candid sample size I heard at the public consultation session, it seems certain I'm not the only one. Nobody backed me, nobody even knew who I was, nobody even cared.

This behaviour is certainly contrary with the United Nations Convention on the Rights of the Disabled. It would appear that although the Deloitte Review and supporting documentation is full of areas that are predicated by those policies, these essential concepts have not trickled down to local RHA support staff for the Community Support Program. I had to hear sour grapes from a bitter, whiny social worker Mr. Egan that he didn't have a new computer in his office when I asked for help finding assistive technology. He was so disgusting I was forced to write his supervisor and get him moved from my case. What a pathetic loser, given carte blanche to bully his way through heav-

en knows how many poor, vulnerable people.

One cannot help but ask if they are actively looking to create problem scenarios among their "clients" because existing in chaos is the only thing that can cover for their inefficiency and complete lack of any progress. They're unable to coordinate even the smallest concepts from the private sector. To every idiot, an opportunity is a problem.

The last "real" social worker I had who had worked in the previous Health Board structure, told me I'd be wise to get on social media about 15 years ago. She knew the focus was no longer going to be on assistance or advice, but presenting obstacles and paperwork.

The assertion that they are making any progress with technology, especially Information Technology is a ruse. Local public discussion on the subject of Information Technology enabling front line delivery of services goes back to 1998 on the Smart Communities Competition, sponsored by the federal Department of industry. The health boards failed to adopt existing technology and apply it to Community Support Services for 20 years, even though every civil servant in Trinity Bay was made aware of what was happening and the issue covered extensively in the media and appearing in practically every community event during that summer.

Government Decision

The Deloitte report is clear that in order for the new individualized funding format to succeed and for the system itself to achieve efficiency and deliver services within reasonable budgets, as has been strongly expressed publicly by both the minister and deputy minister of the Department of Health and Community Services, some sort of quality management protocol is essential for the publicly funded departments and health authority responsible for Community Support Programming.

My association with Total Quality Management Theory goes back to the 90s, when I took a contract with then Western Community College in Stephenville to develop their first promotions and public relations information office, based on developing models utilizing information technology. I was disappointed when quality management wasn't implemented and it was a contributing factor to my leaving the college.

It is critical for government and the health authorities to provide qualitative and quantitative evidence they are helping our society turn a profit socially and financially. It is the direct responsibility of these individuals to be dedicated to improving the lives of their clients. In doing so, efficiencies will save money on the taxpayers' bottom line. Private and public sector initiatives in other provinces to integrate disabled individuals into the workforce and become productive taxpaying contributors are front and center in private-sector disability activism and should be a priority to any Community Support initiatives.

It's time for the regional health authorities and other government bureaucracy to demonstrate the motivation and initiative something akin to what the people on the margins show every day. I've been speaking up for myself much like other more publicly-prominent groups of marginalized people have been speaking up about how they have been neglected and abused. I'm no media darling and I have no affluent, well-connected,

outspoken group working to improve my situation, so I struggle in obscurity.

Government has to legislate quality management into the system or find some expedient method of eliminating the incompetence, redundancy and waste.

Last impressions

This report has outlined the goals for the new individualized funding system, focusing on financial assessment and team support and identifying major obstacles, with the major bottleneck being identified as the regional health authority. The province's minister of health and deputy minister of health have both appeared publicly saying the budget overruns have to be addressed and Community Support programming improve to a point where it can be referred to as a center of excellence.

I'm a disabled person who researched, wrote and designed this report on my own. With voice recognition and the knuckle of my pinky finger. \$10,000 a year below the poverty level. With a cobbled-together assortment of aging technology MacGyver himself would find difficult to reverse-engineer.

I've chosen to take up the challenge of sacrifice and contribution, something more difficult than cashing a cheque full of somebody else's money and calling the cops on a disabled person, who just happened to be better educated and with superior credentials and experience than themselves. And because of that, what I do is inherently more valuable. Like a one-person center of excellence.

"At the end of the day," as the politicians often say when interviewed, at least I tried to do something. From writing press releases for my local MS Society chapter when I was first diagnosed, to raising hundreds of dollars in donation for the society with our business in the 90s, to open letters critical of the health authority, a 14-part series of articles about life with MS all the way to writing an article and appearing in a video for our local accessibility bus service, I've tried to do my part. What did the people I dealt with try to do? They turned their voicemail on and just walked away. Scolded and tried to talk down to me a few times. Never came up with an idea for solving my glaringly-obvious problems first or last. Never spoke up, never stepped up. Displayed what I would say from the perspective of a media professional as a complete lack of presence of mind. They were and are experts in spending your money on themselves.

They have been proven unfit to judge. They saw it all happen and knew what was happening and did nothing. This level of neglect does not align with Newfoundland and Labrador and Canadian values or our history and that disturbs me and my family and friends profoundly.

There has been very little public discussion of the new individualized funding program being introduced by the government of Newfoundland through the health and community services department and the regional health authorities, especially in how it will affect disabled homeowners.

What is needed to address our problems and furthermore, to ensure an effective implementation of an RF program is little more than common sense and initiative and thought and a little bit of intellect.

Recommendations

1. / Immediately begin to develop and implement software solutions for agencies to allow for effective client matching as well as scheduling, in order to standardize the home support work environment across the province.

2. / Immediately align funding to allow self-managed care clients to compensate their homecare workers at the same level as homecare agencies. Giving disabled homeowners and their families the necessary flexibility to take care of their own hiring, scheduling and employee retention would take pressure off the troubled homecare agencies at this time and allow for structural changes to be made.

3. / Examine why the government is paying landlords incredible amounts for rent, yet providing little or no daily practical or financial support to homeowners in the system to directly assist disabled persons stay in their homes as per government documentation.

4. / Government and the RHAs must be immediately priority tasked to take initiative on solutions that would take advantage of existing buying power within the government structure to directly assist disabled individuals to live in their own homes. Especially since the Home First concept was a major promise of the politicians lobbying for the amalgamation into regional health authorities 15 years ago.

As soon as possible the RHAs and government must begin to develop and implement team support solutions utilizing public services for assistance with paperwork, administrative tasks such as tax forms, etc.

Cooperative initiatives should be based around an opt-in app that would provide those dependent on community supports access to surplus government services and utilize government buying power and also allow public workers to volunteer their time and resources to the less fortunate in the system.

5. / Establish a provincial training facility for home support workers in a central location with a defined plan to have it function as a Centre of Excellence. As we have seen in this report, there are serious problems with negligence amongst agency management as well as serious inconsistencies among worker skillsets. The facility must have full demonstration facilities on-site and provide a comprehensive 9-month home support worker program. It must also provide professional development courses/seminars, sensitivity training for public servants who need to understand the rights of the disabled and workers within the province's home support system and serve as the de facto "home" for the industry in the province.

6. / Immediately change the structure which allows home support agencies to make large profits without oversight of spending on technology or support staff. As soon as possible change legislation to enforce how agency profits are directed.

7. / Implement a quality management system across all home support agencies, as they are private companies.

8. / Rollback RHA structure to a more streamlined version, more akin to the pre-amalgamated structure, geared to take advantage of mobile, wireless technology and benefit from less management and increased worker responsibility. Further observations and suggestions are contained in Section 4 of this report under the heading Structural Change.

9. / Fast track layoffs in RHA and government bureaucracy to meet Canadian standard. Eliminate redundant divisions such as rural innovation and irrelevant job positions such as "presidents" and "vice presidents" of services in both the Department of Health and Community Services (HCS) and the regional health authorities (RHA). The return of health authority models to previous board structure would also help to streamline the proportion of bureaucracy and eliminate nonproductive middle-management.

Appendix

Deloitte Review in 4 pages

Executive Summary

- The Newfoundland and Labrador Department of Health and Community Services contracted the firm Deloitte a 16-week, four-phase study of their Provincial Home Support Programs.
- Home support enables individuals requiring assistance with activities of daily living to remain independent in their homes and communities.
- Program currently serves over 7,100 clients throughout the Province with an annual expenditure of \$175 million (FY2014-15).
- The Program needs to address challenges of a predicted significant 14% demand increase and \$53 million funding growth
- Other provinces have simpler financial eligibility criteria and streamlined assessment home support worker (HSW) qualification, and performance management systems, utilizing technology.
- Deloitte broke PHSP into four areas: intake/referral, assessment/planning/co-ordination, home support delivery, and monitoring/policy development, all of which were found inconsistent and lacking.
- A small telephone survey of 131 individual showed most agreed programming meet their basic needs. Satisfaction was lowest among adults with disabilities, a higher percentage who spoke for themselves.
- Review identified evidence suggesting program isn't fully meeting goals as set forth within policy.
- Steering Committee's vision: citizens have access to home support services to help them remain independent, avoid unnecessary hospitalization and long-term care, and maintain their well-being, informed by monitoring and evaluation indicators.
- An efficient and effective Program is needed in an aging society with more individuals with complex needs.
- 25 opportunities to improve the program were identified along with an implementation strategy, including: enhancing assessment tools, implementing hours-based service limits, improving hand-off of service plans, delegating reassessments to paraprofessionals, streamlining financial assessment processes, optimizing financial eligibility criteria and client co-payments, implementing service levels into agency agreements, implementing a performance management framework.
- PHSP is an opportunity to drive change in an integral area of health care system, demonstrate fiscal stewardship and improve citizen health and wellness.

Introduction

- The Program serves over 7,100 clients with an annual expenditure of \$175 million in 2014-15.
- Program grew substantially since its introduction in the 1980s and has experienced significant increases of caseloads.
- Provincial Operational Standards were released in 2005, revised Financial Assessment Policy in 2014. Other changes at HCS and the RHAs influencing program uptake include the

introduction of Paid Family Caregiver option, Palliative/End-of-Life Home services, Short-Term Acute Home Support Services, and the 'Home First' program piloted in Eastern Health. Pressure to adapt and support more individuals and the challenge of sustainably delivering services across a vast geography is constant.

- HCS outlined 13 "project deliverables" areas for Deloitte: Jurisdictional Scan & Literature Review, Program Eligibility, Future Service Demand, Business Processes, Staffing Model, Service Delivery Model, Funding Model, Policy Compliance, Program Goals, Policy Standardization, Monitoring & Evaluation Indicators, Implementation Strategy and Summary Reports & Presentation.

2. Jurisdictional Scan and Literature Review

- Newfoundland and Labrador offers more choice in service delivery than most jurisdictions reviewed.
- Primary and secondary research methods were used, and subject matter experts in Deloitte's Global Health Care Practice were consulted to identify alternative practices and emerging trends. British Columbia, Alberta, Saskatchewan and Nova Scotia are the most relevant Canadian jurisdictions to look toward.
- Other jurisdictions have identified an ever increasing role for non-clinical supports as means to alleviate capacity pressures on institutions and to meet fiscal objectives, with an emerging shift toward paying for outcomes, not simply hours of service.
- Efficiency and continuity of care delivery can be improved through technology.

3. Current State Review

- The review defines the various elements of program delivery and the respective responsibilities of HCS, the RHAs, agencies and clients that form the current program governance structure.
- The key elements of the Program are: *Philosophy, Goals, Key Clients, Service Levels, Funding Model, Service Delivery Model, Assessment, Planning & Coordination*.
- Each RHA has developed its own intake and referral procedures. The intake processes are different to what could be reasonably expected of a standardized business process, raising the issue of consistency or equity of access.
- Improvement opportunities include developing consistent online resources, implementing a provincial centralized and intake and referrals process, improving inter-discipline and collaboration among physicians, nurses and other providers.
- Assessment, Planning and Coordination have several key business process inconsistencies across regions.
- To deliver the most effective and efficient care, it is important to start with a holistic view of a client's health and functional status, and develop an appropriate, comprehensive, reliable, and well-organized service plan that is tailored to the client's needs.

- The interRAI Home Care Assessment System (RAI-HC) is the standardized and automated assessment tool that is used by RHA staff to determine home support needs and eligibility for seniors and adults with physical disabilities.
- From 2006 to 2012, the Province invested approximately \$3.9 million for implementation of the RAI-HC in order to assist staff in the long-term care and community supports services system and to ensure that eligible individuals are offered the most appropriate service options.
- A lack of standards makes it more difficult for RHA staff to develop objective service plans solely based on unmet client needs.
- CHNs and SWs are responsible for administering and interpreting the clinical assessment to ensure consistent administration and application of the tool, cross-professional training is required.
- Eligibility determination and service planning could be improved by utilizing evidence-based assessment method that focus on client function and considers caregiver stress.
- Financial assessments are completed by Financial Assessors (FAs). Financial reassessments are performed on an annual basis at a minimum.
- FAs have between 490 to 720 financial assessments/reassessments performed per FTE per year depending on the region.
- All financial data related to clients, including approved service hours, client contribution levels and financial subsidy levels are keyed into the Client Referral and Management System (CRMS) Pay Module.
- Jurisdictions within Canada and the United States are beginning to shift their focus to paying for outcomes rather than the hours of support provided.
- This model requires strong oversight, contracts or Service Level Agreements (SLA) to establish performance criteria, ongoing monitoring and reporting, and data sharing between government and service providers.
- Some staff and clients consider the financial assessment process to be complex and burdensome.
- General determination of client contribution, if it exists, is a much simpler process in other jurisdictions.
- There are summary indicators showing that the direct resource cost of completing financial assessments is relatively low compared to the savings generated.
- The PHSP Operational Standards (2005) allows for exceptions to be made at the discretion of RHAs.
- Clients with intellectual disabilities receive the highest number of exceptions among the three client segments (at 7.0% vs. 2.3% for physical disability, 1.7% for seniors, and 1.5% for SCWA).
- Adults with disabilities require more community inclusion and lifestyle coaching services. In addition, adults with disabilities and SCWA require more flexibility in how they use their approved hours.
- Eastern Health is more willing to approve exceptions due to the desire to alleviate acute and LTC system pressures in this region. The implementation of the Home First program and

other initiatives in Eastern Health could be another contributing factor.

- For clients using agencies there is little to no communication between the RHA and agency about the clinical assessment or need. The clinical assessment seems to be used solely by RHAs in order to determine clinical need and eligibility.
- Expanding of the individualized funding model, which would provide a monthly budget or block funding to the client, would allow the client to use their approved hours and subsidy as they see fit. The Program would be more responsive to clients' changing needs as well.
- Higher amount of service hours approved per client in Eastern Health may be due to the region, and specifically St. John's, providing services to a larger volume of high complexity needs.
- In 2014-15, Labrador-Grenfell Health spent the most for each senior served (\$18,320) while Western Health spent the least (\$16,744). RHAs expenses for seniors have been very consistent across the Province with a low of \$17,271 to a high of \$17,618. For adults with disabilities, Central Health spent \$32,667 followed by Eastern Health at \$30,753 for each client served. Western Health spent the least at \$25,916. Central Health spent the most to support children with disabilities at \$20,317 per family served while Labrador-Grenfell Health spent \$10,902.
- Nine improvement opportunities were suggested in the report, including: implement hours based service limits (as opposed to financial ceilings), augment the clinical assessment tools, perform risk-based reassessment of client needs, delegate reassessments to supervised RHA paraprofessionals, streamline financial assessment, optimize financial eligibility criteria, Improve the hand-off of service plans to agency and SMC providers, expanded individualized funding, promote the sharing of services and supports, and integrated care plans.
- Program recipients may avail of agency based care or employ their own Home Support Workers (HSW) under a Self Managed Care (SMC) arrangement with RHAs responsible for monitoring service plans and client outcomes.
- Program offers considerable choice relative to other jurisdictions, with agency-based care the predominant service delivery option selected. There is a trend away from SMC despite access to a greater number of daily service and hours. (Maybe connected with lower rates of pay.)
- 39 unique agencies are registered with the RHAs and operate under the terms set forth in the Operational Standards.
- Agencies cite the attraction and retention of qualified HSW as a problem, but have not been investing into integrated hiring initiatives, client-worker matching or proper promotions marketing.
- Communication gaps and a lack of visibility on underlying client needs contributes to inefficient and ineffective service delivery.
- Consultations with home support agencies and client advocacy groups suggest insufficient monitoring of home support services by the RHAs and absence of ongoing monitoring of client outcomes and collaboration with agencies.

- Wages for HSW are lower than those for Personal Care Attendants who fulfil a similar role in residential care settings in the Province. This wage differential and a greater consistency of hours in residential care is understood to contribute to challenges associated with the attraction and retention of competent HSW.

- Unlike other Canadian jurisdictions that have formal mandated qualifications for HSW, no educational standard exists for the PHSP and agencies retain responsibility for determining the scope and delivery schedule of training programs.

- Consultations with Program stakeholders revealed concerns about the quality and variability of service, the willingness of home support agencies to provide and fund training and an inability for the Program be responsive to client needs through matching HSW skills and competencies to the complexity of care requirements.

- Lack of defined service levels and a systematic performance management framework obscures visibility on the extent to which Program and client outcomes are being achieved.

- Jurisdictions such as Nova Scotia are seeking to expand beyond service agreements and are exploring contractual arrangements where agencies are remunerated on the basis of the client outcomes.

- System must build on the current operational standards for agencies but include reference to such quality indicators as the required skill set of HSWs, monitoring of service hours provided, client/family complaints, the ongoing health status of the clients being served by the agency, among other factors.

- HSW availability and qualifications are key common themes that emerged in reviewing the SMC option. Additionally, a lack of oversight by home support agencies or the RHAs result in challenges associated with HSW training and qualifications are exacerbated for SMC clients. Stakeholder consultations also suggest that this lack of oversight may also lead to an increased risk of abuse for vulnerable clients.

- The review suggested ten opportunities for improvement, including: establishment of agency agreements with embedded service levels, an accountability framework that supports a standardized program, reduce the number of agencies, exploration of alternative funding arrangements with agencies to shift focus to client outcomes, improve the hand-off of service plans to agencies and self-managed service providers, policies, processes and technology enablers to monitor client trajectory and outcomes, policies and processes to guide the provision of informal supports, Define HSW qualification and education requirements and strengthen monitoring policies, streamline SMC administration.

- There have been no substantial changes in the current operational standards manual since it was released in 2005, while there have been policy changes at the HCS and RHA levels that are influencing the uptake of the program—paid family caregiver option, palliative and end-of-life home services, short-term home support services to avoid hospitalization, and Eastern Health's 'Home First' pilot.

- There was a phone survey of 131 participants, using an

11 question questionnaire during February and March 2016. The clients were drawn from lists of clients supplied to Deloitte by the RHAs according to pre-determined criteria. The clients were asked to rate their level of satisfaction with the Program.

- The results proved quite supportive of the Program overall, with turnover in Home Support Workers and the application process noted as key challenge.

- Client survey results indicate satisfaction with the Program is lagging for Adults with Disabilities.

- The consultants did not find any key program indicators or an overall performance framework to guide implementation of the Program or measure its performance.

- The Program is working well in terms of its primary goal but there is no ability to say exactly how or where it can improve outcomes. While most internal and external stakeholders believe the Program is meeting goals, there is no independent evidence to support this view.

- The review was not able to address the goal of allowing individuals to have choice in how they live.

- There are no consistently-reported key performance indicators or an overall performance framework to guide delivery of the Program or measure its success.

- Owing to the distributed nature of data entry into CRMS by RHA Community Health Nurses and Social Workers, there are significant quality issues with the data captured.

- Stakeholders expect to be able to participate in the ongoing improvement of the Program.

4. Future Demand for Services

- Two future demand models have been designed to enable scenario development and sensitivity analysis by each RHA and client group.

- The first model is strictly for the Seniors client group, and the second incorporates both the Adults with Disabilities and SCWA populations.

- The models make use of historic caseloads, approved service hours, and expenditures to develop projections.

- In summary, the demand model illustrates quite clearly that caseloads are going to increase significantly through 2021, largely due to the demographic changes being faced by the Province. As such, without intervention, the Program costs are going to see significant increases with medium estimates predicting that the Program costs will increase by \$53.4 million through 2021. In order to keep costs stable in this Program, significant policy changes and/or operational improvements will be required.

5. Future Program Vision

- The proposed purpose statement, developed in close consultation with the Steering Committee, for the Provincial Home Support Program is: high quality, client-centered, collaboration, choice in determining, timely manner, independence, safety, inclusion.

- A series of goals and objectives were required for the next five years of the Program. Proposed future goals for the Program and associated monitoring and evaluation indicators

were drawn from the review.

- A key feature of a modern program management regime is to have an appropriate performance measurement framework in place, currently lacking for the PHSP.
- HCS will need to commit the time and resources to collect, analyze and report on the data.

6. Improvement Opportunities

- The emphasis of the review was to identify potential opportunities to improve the efficiency and effectiveness of the PHSP with a view to its long-term sustainability.
- The impact that future demand will have on the Program was also critically examined to identify opportunities to mitigate any increase in Program resources as a result.
- Various improvement opportunities were noted as the current state of each area of the Program was reviewed in Section 3.
- The identified opportunities are differentiated between either improve Program Effectiveness or Efficiency across program Intake & Referral/Assessment, Planning & Coordination/Home Supports Delivery/Monitoring & Policy Development
- Not all opportunities are equal in terms of ease of implementation and their degree of impact on the future of the Program.
- Improvement opportunities were prioritized on the basis of impact and ease of implementation and divided into four areas: Quick Wins, High Priority, Advance With Patience and Consider Last.
- Understanding program financial sustainability was an important goal of the review.

- A medium-demand scenario was assumed.
- The analysis presented policy choices to demonstrate how future sustainability of the PHSP can be assured.
- Annual subsidy expenditures were forecast to increase by \$53.4 million over the next five years.
- The review indicates the province could mitigate the financial impact of increased demand for home support services, providing home supports at or below current funding levels while maintaining or improving service quality by:
 - Maintaining the two-hour cap on homemaking hours, maintaining the maximum client contribution of 18%, Enhancing clinical assessment tools, Implementing service levels in agency agreements and achieving a level of consolidation, lowering the financial eligibility ceiling from an annual income level of \$150,000 to the median provincial annual income of approximately \$35,000.
 - Estimated Changes to Annual Program Subsidy Expenditures, Estimated Changes to RHA Resourcing Requirements, Description of Changes to RHA Resourcing Requirements are summarized in tables.
 - An opportunity exists for the RHAs to mitigate the impact on resource requirements resulting from increased demand for home support services by implementing high priority efficiency improvements.
 - A five-phase, five-year implementation strategy roadmap was developed to support prioritization of opportunities.
 - HCS and the RHAs needed to dedicate existing internal resources to implementation of the improvement opportunities. Most didn't need additional resources to implement, but there was need for specific expertise not readily available.

Q & A

Dept. of Health & Community Services

I wanted to speak with the individual in government responsible for the plan described in the Deloitte review. I was directed to Joanne Rose, MSW, RSW, Health Consultant for the Department of Health and Community Services

Although I was not given a real individual to speak with, I was permitted to submit a list of questions.

As noted previously in this report, there is an obvious disconnect from a government department claiming goals were met and achievements made and quantifiable improvements actually occurring in the lives of vulnerable individuals in the province, when there is no oversight from any outside group. As indicated, the NLCOPD (Newfoundland and Labrador Coalition of Persons With Disabilities) is not an independent organization, rather only an arm of the HCS.

As also shown earlier with the “consultation sessions” surrounding the IF initiative, the department actually thinks that just because they were told certain events happened, they can take credit for something and pat each other on the back.

Most likely my question is the first encounter the department’s staff have had with any criticism of the consultation process. Most likely, like in Cold War communist systems, the RHA will not acknowledge they have caused any of the problems and have had innumerable opportunities to fix them.

It is worth noting that many of the same groups, job distinctions and even the same individuals were listed in appendixes as either stakeholders or having been consulted for both Deloitte’s review and the Health Accord document.

This realization leads to questions about the Health Accord NL’s potential for success. How can the same individuals responsible for creating an environment of failure they will not take responsibility for transform a health system for the 21st century?

Question #1: *How high a level of success does HCS feel the five-year implementation strategy outlined in Deloitte’s report achieved? How many of the opportunities outlined were able to be taken advantage of? How many goals for 2021 were met? Recently, we’ve heard quantifiable value in the system has been improving due to efficiencies. Are any of those attributable to the implementation strategy?*

A: The Deloitte review of the Provincial Home Support Program provided 25 opportunities/recommendations to improve the efficiency and effectiveness of the program. Government accepted the report and all recommendations and establish an advisory committee to oversee implementation. To date, eleven of the opportunities have been fully completed, thirteen have been partially completed, many of which have been substantially completed, and one has not commenced yet.

Question #2: *Did the streamlining of the yearly assessment process result in achieving any quantifiable improvements? Was there any positive feedback regarding the shorter form? Now that yearly client assessments are totally based on ROI,*

are there concerns about interruption of service if a client is unable to do the CRA tax return themselves? Will HCS/RHA provide tax services for disabled individuals who have physical or learning challenges? Were there concerns about families taking legal action if a client lost service?

A: The financial assessment should be completed after a clinical assessment has determined the client has an unmet support need that requires formal services. Both assessments are reviewed on an annual basis. Regarding the financial assessment, the income test was used by home support only clients since 2009, it was expanded to all home support clients in 2019. This is a more streamlined process for clients as less documentation is required for the financial assessment, no formal evaluation/feedback process established to gather client opinions on the change. The financial assessment is based on the Net Income as reported on Line 236 of the Notice of Assessment. The issue of clients being unable to complete a tax return has not been raised to the Department. We are not aware of any cases where the regional health authorities has been asked to provide or support the payment of tax services for clients. The regional health authorities will work with clients to have appropriate documentation submitted and would not suspend services without discussions with clients and an attempt to resolve the issues in providing appropriate documentation.

Question #3: *What did HCS consider the greatest obstacles? What opportunities turned out to be the most advantageous? There has been significant commitment by key stakeholders to work together to reform the Provincial Home Support Program.*

A: It is difficult to identify one opportunity over another as being the most advantageous, as many of 25 improvement opportunities are interrelated and need to be implemented together to create change in the delivery of the Provincial Home Support Program.

Question #4: *Are initiatives in the work for standardization of homecare training and qualification? How open would HCS and the RHAs be to a centre of excellence operated by CNA in a central location?*

A: The Department of Health and Community Services has established a working group to develop an educational strategy for home support workers in the province. The final report and recommendations are under development. Currently, there is a review underway to revise the post-secondary educational curriculum for the Home Support Program offered by public and private educational institutions in the province.

Question #5: *Would HCS be open to a public examination of provincial home care agencies as to identifying the most serious problems and finding the most effective solutions before there is a crisis? Are any quality management initiatives going to be implemented with HCS and RHA employees? Would HCS*

be willing to implement quality management in the homecare agencies for case officers and management? What shape would the process have to take?

A: The Department of Health and Community Services is responsible to develop operational standards for the establishment and operation of home care agencies. The regional health authorities are responsible for the approval and monitoring of home care agencies including quality assurance initiatives to improve the effectiveness and efficiency of the delivery of home support services in the province. If you have any specific concerns regarding a specific homecare agency, these concerns should be reported to the responsible regional health authority.

Question #6: *Is HCS aware of the problems with the IF sessions from 2018? Homecare management reported very questionable popular education techniques to me, totally inconsequential and poorly executed. I took popular education technique sessions with MUN's Bruce Gilbert, who is recognized as the province's pioneer expert in the field, when I was teaching journalism at the college in Stephenville. Furthermore, the director of the NLCOPD wouldn't tell me what the cost of the sessions were, or who was paid to carry them out. Can you tell me what that figure was? Personally, as a former college instructor and an information officer for the college, I found the facilitation unprofessional and poorly organized. When I tried to get involved with the IF sessions, they were ill-prepared, kept changing their location and when at one point the facilitators didn't return my call, when I managed to catch up with them, the woman on the other end of the phone laughed at me. I was excluded from attending a session, only allowed to listen in via a terrible phone line, also poorly set up. The presenters tried to paint that poor man Layton Deigh as an expert, even though he repeatedly attempted to explain who he was. I was told that the homecare community believe they are adopting the Australian model, and that's all they know. The sessions were an em-*

barrassment. What does HCS think about that chain of events? This was a comedy of error caused by ineptitude. What can HCS do to increase its professional effectiveness and prevent these type of mistakes happening in the future?

A: In 2017, the Newfoundland and Labrador Association for Community Living (NLACL) and the Coalition of Persons with Disabilities Newfoundland and Labrador (COD-NL) were contracted by the Disability Policy Office, Children, Seniors and Social Development to hold community capacity-building sessions and social design labs on Individualized Funding which was completed in the fall 2017. Sessions with stakeholders were held at locations around the province to review the current funding model, to hear about people's experiences with our current model, to explain the premise of Individualized Funding models, and to explore, and gather information about, those characteristics and details stakeholders wish to have considered and included in an Individualized Funding model. A final report was prepared for and shared with Disability Policy Office, Children, Seniors and Social Development April 2018. Please contact Disability Policy Office for further information.

Question #7: *It has been noted to me multiple times in the previous 48 months that there are no true Independent organizations representing the disabled community at large in the province. A cursory examination of the list of individuals consulted for the report shows it is almost completely comprised of not clients, but those benefiting professionally from taxpayers. Will HCS commit to a process for recruiting and inviting well-qualified critics chosen by disabled Newfoundlanders and Labradorians?*

A: It is our understanding that individuals with disabilities and their primary support persons were engaged in the community capacity-building sessions and social design labs on Individualized Funding completed in the fall 2017. Please contact Disability Policy Office for further information.

Backgrounder

Barry Moores

Barry Moores grew up sharing his time between Cottrell's Cove and Clarenville, Newfoundland. His father, Milton Moores, was a veteran of Newfoundland's 59th Heavy Artillery Regiment during WWII and earned his living as an agent for insurance companies and as an inshore fisherman and woodsman/trapper. His mother, Stella Granter Moores, taught school in Clarenville from the late 1940s until the early 1970s.

Barry earned an honours degree in journalism from the University of Kings College in Halifax, NS in 1988, where he was also valedictorian. He worked as a reporter and editor for newspapers in Grand Falls/Windsor and Lewisporte, taught journalism for two years at Stephenville and went on to create Western Community College's first information office in 1992, utilizing emerging information technology in its framework. Following 18 months as an announcer/operator and writer/broadcaster with CBC Radio in Corner Brook, where his mini-doc about MS was a co-winner of the Canadian MS Society's Media Award, Barry moved back to Clarenville in 1995, after completing 12 entries for the Encyclopedia of Newfoundland and Labrador.

In cooperation with another local media specialist, Barry created Natural Media, the first full-service media agency in rural Canada, an enterprise which broke new ground in graphic design, copywriting, photography, on-demand digital printing and media services. It should be noted Barry started this endeavour after he was diagnosed with secondary progressive multiple sclerosis.

Natural Media was the first advertising and promotions agency in rural Atlantic Canada to combine strategy, design, copywriting, printing and distribution services under one roof. At its high point, Natural Media employed eight full-time and a half-dozen part-time employees.

Among Barry's cutting-edge projects were the Cabot 97 Bonavista Historical map project, the 1998-99 Discovery Trail Tourism Guides, (the most comprehensive of their kind ever published), promotional materials for Clarenville's initial 1995

Telematics Strategy and subsequently Action IT, creating the name and all identity materials for the Terra Firma IT conferences, developing all media releases and promotional materials for the regional Smart Communities Contest entry, serving on the development team for the Random Access IT Cooperative, and working as executive editor, graphic designer and copywriter for the first Distributed Learning Website of the College of the North Atlantic. He also came up with the name and designed the poster/brochure for the original Random Sounds Music Festival. In 1996, at the request of the Discovery School District and College of the North Atlantic, he gave a series of speeches in schools across the Discovery region concerning entrepreneurship, education and disability.

After Natural Media, Barry was in the first generation of online freelancers, providing writing and design services for clients locally and internationally. Before retiring from commercial work in 2006, he specialized in 20th century vintage themes. His 50s menu design for a local restaurant has been viewed over 1000 times at his online portfolio: www.behance.net/BGM. He was featured in article about logo design in Atlantic Business Magazine in 1998. His writing, design and media distribution was a key element in the successful Save White Hills 2000 campaign.

In the last decade, Barry's article about the CREST bus service appeared in newspapers provincially and was one of the local people featured in the CREST promotional video. (<https://www.saltwire.com/atlantic-canada/holidays/a-personal-perspective-crest-bus-an-essential-service-125123/>)

He's a tireless advocate in the media for disability issues and a 21-year associate member of the Canadian Legion. His friends showed their love and respect by holding the Music For Moores concert at the Clarenville Events Centre in 2012. In December 2016, he released an unprecedented series of 14 articles about his life with disability, which was also covered in provincial media. He contributed to the regionalization sessions in Clarenville and in 2019, he ran as a candidate for the NL Alliance in his local district and received nearly 500 votes.

Coping with MS life-long process

By FRANK CARROLL
Star Staff Writer

STEPHENVILLE — Barry Moores is trying to live a healthier lifestyle these days.

He has no other choice if he is to contain the symptoms of multiple sclerosis.

Moores, a public relations officer with Westviking College, found out in January that he has the potentially paralyzing disease. Most people would react in horror. But Moores surprised himself by taking it in stride.

"Sometimes even a flat tire can make me panic, but it was almost an immediate acceptance," he said.

Moores was relieved to know what he was up against after weeks of physical examinations and months of mysterious symptoms.

It all began last summer when Moores started losing his balance from time to time. At first he dismissed it as an inner ear problem or a pinched nerve, promising himself that he would one day have a doctor check it out.

But as the year progressed, Moores began experiencing other symptoms. One night last summer, he lost the ability to move his left leg. It got better the next day, but eventually the problem reappeared. Fatigue also plagued Moores, so much so he found it difficult walking up a flight of stairs.

Just before Christmas, he again lost the ability to move his left leg and felt small currents running through his right one.

On Jan. 10, a neurologist diagnosed him with multiple sclerosis. He is one of more than 50,000 Canadians with the disease.

Multiple sclerosis attacks myelin, the insulating cover of the central nervous system. The myelin becomes inflamed and may be replaced by scar tissue. Messages from the brain are slowed or blocked.

Symptoms of MS vary from person to person. They include problems with seeing or speaking, extreme fatigue, loss of balance, weakness, numbness or loss of coordination.

Although Moores reacted well to the news, he found certain things about the disease aggravating. For example, he was unable to tie his own necktie for a while. But treatment has allowed him to resume simple tasks.

Moores said there are three basic types of MS. With one type, the initial symptoms remain constant, staying with a person for the rest of his life. A second type may see the person go into remission.

He believes he fits somewhere between these categories. If this is true, he is one of the more fortunate people with MS. A third kind is degenerative and eventually leads to paralysis.

Moores should have a better idea soon as to what kind of MS he has. He will undergo a test to determine which parts of the spine and brain are affected by the disease.

Nobody has found the cause of MS. But there is evidence that genetic factors may be involved in determining who is susceptible to it. In Moore's case, for example, two other people in his extended family have been diagnosed with MS.

For some reason, multiple sclerosis is most common in the northern hemisphere. However, warm temper-

atures tend to aggravate symptoms for those who already have the disease. Moores, for example, said he had to be careful during a recent Caribbean cruise.

Indeed, Moores now has to be careful all the time. He must stay away from alcohol, avoid cigarettes, fatty foods and stress.

He said he does a lot of little things to keep healthy. He gets plenty of sleep, takes multivitamins and vitamin B-12, and tries as much as possible to maintain a positive outlook.

Cortizone steroids have been especially effective in keeping the disease in check. Moores doesn't shake as much these days and can perform light tasks.

"It's always important to have a reserve of energy," said Moores.

He said people with MS shouldn't be afraid to let others do favors for them. Nor should they be shy about approaching things differently.

"If you've got to wait in line for Rush tickets, bring a lawn chair," said Moores. "Don't stand for a long time. Use a cane while walking if you have to."

"But don't be afraid to take walks. You've got to keep your health up. You've got to realize that it's a life time process. When you've got it you've got it."

The MS Society established a branch in Bay St. George area last week. For further information, contact Diane Branton at 643-9201.

**Western Star
Corner Brook, NL
1993**

By RAPHAEL BORJA
THE PACKET

With a little help from his friends

Campaign aims to help MS-stricken writer

Barry Moores is looking to the future to get back working, thanks to the charity of friends.

"I've watched his MS progress," says longtime pal Steve Somerton, who looks up to Moores as a mentor. "It's pretty disheartening to see it happen to your friend."

Earlier this August, Somerton started an Internet fundraiser — called Friends of Moores — to buy Moores a new computer system.

So far, the campaign has raised \$670 of its \$3,905 goal.

"The support has been pretty good, from complete strangers to his closest friends," says Somerton. "Exposure — just getting the word out — is still the (campaign's) biggest challenge."

Moores, a writer and journalist who has worked all over the province and now lives in Clarendville, was diagnosed with multiple sclerosis about 17 years ago.

"I went from being a very mobile, physical individual to realizing that I was going to skid over a period of time. How long, I had no idea," says the 44-year-old. "That's the thing with MS — you never know."

In 2002, Moores became confined to a wheelchair. Today, he requires 24-hour home care.

Learning to adapt with the disease has been a "massive challenge" for Moores.

"You have to put together some

type of framework — an organized chaos — so you've got something to lean on," says Moores, who grew up in rural Newfoundland. "I lean back on the stories of independent, in-shore fishermen. As I learn more about my genealogy, I lean back on their lessons."

In addition to the hardships, Moores' disability has also, ironically, enabled him to learn new skills.

"I've been working to learn how to use speech recognition software — I'm pretty slick with it now and my radio voice is better than ever," says the former broadcaster, who can no longer type with his hands.

"Computers is where I have to place my reality and adjust myself, because I'm not physically robust as I am digitally robust," he says. "Work-wise, it's where I live. It's important I have a good set of tools, and the most important part of my toolbox is the computer."

The laptop he's using right now is growing long in the technological tooth, which is why his friends are campaigning for a better system.

"It's at the end of its serviceable life. It overheats, it locks up, it takes inordinate amounts of (maintenance) to keep it to a point where I can half-trust it for the next day."

With a newer, more capable

computer, Moores hopes to finish his a 450-page historical novel — tentatively titled *Dishonest Meals* — that draws much inspiration from his rural Newfoundland background.

"It's more character- and texture-driven, more so than locality, so it would be relevant to anybody who lives on a coastline," he says on the book's universal appeal.

The novel started five years ago, after he stopped freelancing full time, when he came to a natural milestone of his career.

"When I started off as a journalist in the '80s, I knew at some point I had to (tackle) something of large format. You were either going to do documentaries or large magazine work or a novel," he says, adding that the long-term project also helps him stay focused when times get "demoralizing."

He's also in the process of digitizing and compiling an online portfolio, featuring his work over the past three decades.

Some of Moores' best works come from his stints as an intern for the *Newfoundland Herald*, reporter for the *Advertiser and Pilot* and graphic designer for his printing services company, Natural Media.

"I'm still young enough to go

back to what I was doing before," says Moores of his professional future, planning on using his manuscript and portfolio to market his skills.

Though he's still getting by with his dying computer, Moores is happy with the support he's getting from his friends, especially after his

frustrating failures of trying to get funding through governments and bureaucracies in the past.

"I'm really getting a sense of the kindness in the community. It's something I knew before but this verifies it."

"I'm tremendously grateful... it's really hard to put into words," says the seasoned wordsmith. "Maybe English just doesn't have the capacity for it," he smiles.

To donate to Friends of Moores, visit friendsofmoores.blogspot.com.

rborja@thepacket.ca

**The Packet
2010**

Lack of preventative medicine leading to complications

Dear Editor,

Due to the failure of Eastern Health to provide footcare, I have suffered a serious injury to my left foot, one if I'm unlucky might lead to amputation of my big toe.

I'm a pensioner confined to a wheelchair, reliant on public services for my home care and support as I struggle to live independently with my condition, multiple sclerosis.

Trying in vain

For more than six months, I have repeatedly approached my social worker warning about the danger to my health if the footcare situation was not addressed.

Eastern Health was unable or unwilling to secure footcare for me.

Last week, my toenail cracked and became infected.

To add insult to injury, when I contacted my social worker's office and told them I would now have to see my doctor, the latest replacement social worker didn't even bother to apologize for their horrible failure, as if it was my fault.

As I am housebound with no transportation, and the Clarendville area is bereft of any transportation for disabled individuals, my doctor had to visit me.

He was obviously alarmed and instructed me if the infection worsens I will have to immediately go to ER in an ambulance. There is considerable danger it will worsen and I am trying to keep the foot elevated. I am also taking antibiotics.

As my physician accurately says, for a fee of less than \$50, the health

board could have prevented this painful injury to a citizen they are paid to protect.

Now there is a real possibility their neglect will result in the further expense of thousands of dollars of taxpayers' money for ambulance services and hospitalization.

I'd attach a photo, but it's too gross.

My doctor agrees this neglect is likely a strategy designed to break my spirit and destroy my health to the point where I would need to be institutionalized. One crippled bayman wanting to live independently is apparently too complicated for an office full of self-described and publicly funded health experts, which is a disturbing level of incompetence.

My doctor tells us Eastern Health seems to think if they ignore me long enough, I'll go away and leave them alone.

No surprise

Worst of all, I'm not surprised: in my case they've failed in most everything they've been tasked.

The most pathetic recent example is their inability to supply a com-mode they promised nine months ago. I don't have the room in this letter to get a list started.

Even beyond the systemic incompetence behind my painful toe, their sense of entitlement is the most troubling.

I've been in the Eastern Health system for 15 years, through all levels of specialists, counsellors and social workers - in December there was a full-page feature in the

regional newspaper concerning a fundraising campaign for me - but honest to God, last week when I called to discuss grocery delivery, the latest replacement social worker dismissed my concerns immediately, criticizing my questions and interrupting me with some drivel about Internet banking.

It was sickening to realize after a decade and a half, they didn't even have a file. Not a clue.

Those who don't know are leading those who don't care and most likely the other way around as well.

The big question is: what else haven't they done and who haven't they done it for? In military terms, they have the situational awareness of a dead cow. They are combat ineffective.

They are living high on your money, they never had it so good and they know it. The current government doubled health spending this term but you'd never know it from here on the margins.

Eastern Health was arrogant and heedless with the wrong crippled bayman this time. I don't care.

If I lose a toe, I'll lose my other foot up somebody's ingrate ass. I certainly won't be forced out of my home.

Sincerely,
Barry Moores
Clarendville

Packet/Telegram et al
February 2011

System breakdown

Lack of preventative care leads to complications

By MALLORY CLARKSON

THE PACKET

For most people, the simple task of grabbing clippers from the bathroom, bending down and trimming each toe is second nature.

But, for Barry Moores, a housebound, Multiple Sclerosis (MS) patient, confined to a wheelchair, it's complicated.

He can't bend down and do it himself. His home care worker can't do it because of regulations.

Because of his condition, a professional must do the clipping. A nick or cut could be detrimental to his health because of his MS.

In fact, that's the situation in which Moores now finds himself.

Because of the time that has passed since his last professional trimming, his big toe nail became overgrown, then cracked. Now it's infected.

His doctor prescribed him antibiotics to fight the infection. Moores has to keep his foot elevated all day. The medication is helping his toe, but is wreaking havoc on his body - aggravating his MS symptoms.

He's worried that if the infection worsens, his big toe may have to be amputated.

Moores is at his wit's end.

A nurse was coming in to provide foot care for him for quite a while. However, he said that service ended six months ago.

Options

According to Jackie O'Brien, media specialist with Eastern Health, home and community care nurses employed by the organization do not provide foot care.

She added it's not Eastern Health's mandate to do so.

She told **The Packet** there's a system through Eastern Health to direct patients to private practices who can provide specialized care, but it's up to the patient to, "Make contact with the health

Please see page 8

Continued from page 1

care provider, set up this type of care and take responsibility of their own health care."

She explained the home and community care nurses employed by Eastern Health offer acute care services, chronic care and chronic disease management and support, assessment for placement to long-term care, home supportive services and palliative and end of life care.

O'Brien added if a client can't leave their home, home visits are available.

Although post-hospital care, like dressing changes, is provided by these nurses, preventative maintenance, like foot care, isn't offered.

As for Moore's contention that nurses who were providing foot care to him could no longer do it because of their workload, O'Brien confirmed there are two community nurses providing services in the region. The area they serve includes Random Island, South West Arm and the Harcourt to Clarendville area.

She also confirmed there are three such positions assigned to the area, but one position is vacant. It will be filled as of March 7.

Asked whether registered nurses have to go through a special course to provide foot care to patients, O'Brien said, "We believe that is correct."

"However, we are unable to comment on how many nurses have this certification or how many clients require this type of care, as it is not a service that is offered by Eastern Health."

The process

O'Brien explained people who may need foot care service may be able to qualify for financial assistance to help pay for private service.

She says social workers can assess the client's needs and provide proper information and access to services.

"For example, they (social workers) may decide a client needs 24-hour (home) care or they need foot care. If the client needs foot care, they direct them to where they can find that service."

She noted if a patient needs foot care, this is the avenue to follow, adding Eastern Health cannot comment on specific cases.

Moores said he has already gone through this process.

He told **The Packet** he kept calling his social worker every couple weeks to get the service, to no avail. He also called his doctor to come into his home to look at his split toenail.

"I didn't think I had to go any further (than) my social worker and my doctor - those were the people I talked to," he said. "It wound up getting tossed into other correspondence."

"I didn't keep anybody in the dark about this."

According to Moores, the two nurses in Clarendville that provide this care to

"They're not called Eastern Mechanical (and) they're not called Eastern Carpet and Flooring - they're called Eastern Health. Where are these services that I was led to believe were the mandate of this organization?"

- Barry Moores

him in the past had full slates and couldn't continue caring for him.

O'Brien contends, however, there haven't been any cases of home care ceasing.

"There is no wait list for home and community care services; clients are admitted to and discharged from the program based on the nurses' assessment of a client's needs," she told **The Packet** in an email.

"The demand for home and community care services has increased over the past year; however, this has no impacted service delivery and there is no incident of where our nurses have not been able to provide a service," she said.

Absurd

Moores, meanwhile, says he hasn't yelled or caused a scene; rather he has patiently pestered people in the process - he just wants his toenails trimmed.

"It's absurd," he told **The Packet** last week. "If they could find a solution as quick as they find an excuse, we'd be off to a good start here."

He said this could be considered systemic failure for Eastern Health.

"They're not able to put together the simplest of needs," Moores said, adding health care should be second nature to Eastern Health.

"They're not called Eastern Mechanical (and) they're not called Eastern Carpet and Flooring - they're called Eastern Health," he said.

"Where are these services that I was led to believe were the mandate of this organization?"

Moores said he isn't asking for much - his main interest is to get his toe and the system fixed.

"If there's some systemic failure in that organization with delivering services to people, then that should be fixed," he said. "If I had this problem fixed, it may link into getting other problems fixed."

(To see more of Moores' story see his Letter to the Editor on Page A7)

mclarkson@thepacket.ca

Packet/Telegram et al
February 2011

The Stationary Hobo

2017

Barry Moores chronicles a 25-year battle with MS

BY DANETTE DOOLEY
SPECIAL TO TC MEDIA

Barry Moores' work is as gripping as it is sad.

Moores, who lives in Shoal Harbour, has just compiled a series of short stories about his life with Multiple Sclerosis.

Tales of the Stationary Hobo and the Theory of Nothing is a compilation of 14 short pieces, with graphics. It's the story of his life from his initial MS diagnosis almost 25 years ago, to now and the challenges he's faced over the years.

Moores worked as a journalist, broadcaster, researcher, entrepreneur and educator - beginning his career in 1985. He was in his 20s when diagnosed with MS in 1993.

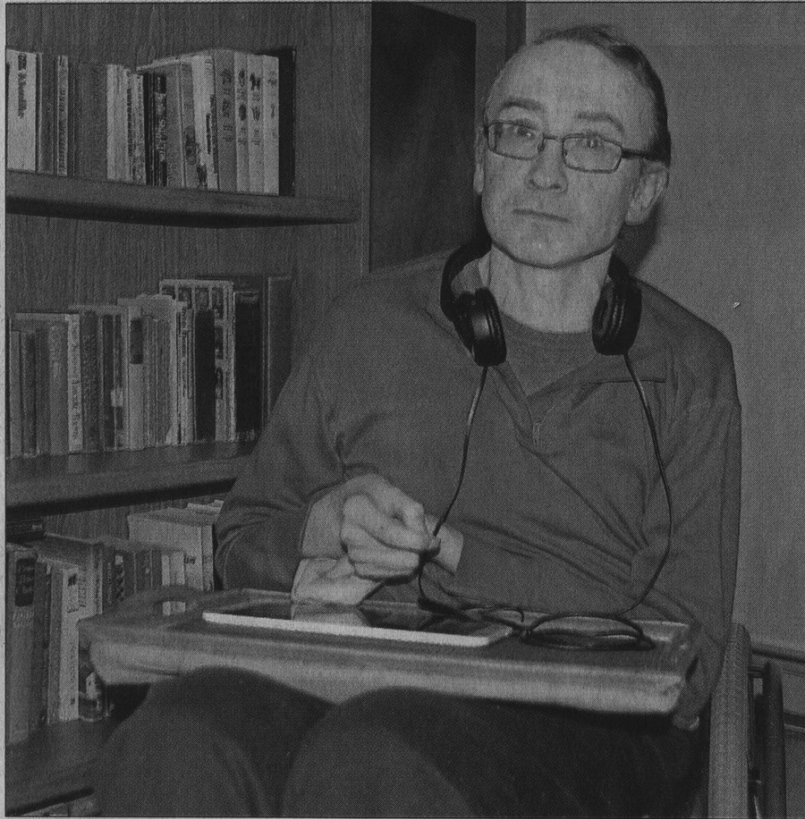
A piece he produced for CBC radio at the time was co-winner of the national Vickers and Benson 1995 MS Media Award.

In *The Stationary Hobo*, Moores's flair for writing comes through in every sentence. His stories are compelling, thought provoking and, at times, funny.

Moores doesn't look for pity. Rather, takes a straight-forward, honest, approach to his writing. Moores writes that he lives with intermittent bouts of depression, panic, anger and anxiety. (It wasn't lost on Moores that this phone interview about his writing took place on Jan. 25 - Bell Let's Talk Day - a day set aside to help raise awareness about mental illness).

"MS and its complications have broken me physically, stripped away my identity and erased pretty much all of my life and the expectations I had for it, leaving me with stress and anxieties too numerous to count, on top of the disability and pain.

"My survival has come with



JONATHAN PARSONS PHOTO

Barry Moores in his Shoal Harbour home; the longtime journalist has just written a series of stories about his decades-long battle with Multiple Sclerosis.

great psychological damage, but the patches I put over the holes have managed to stick. Up to this point it's been my personal and private struggle," he writes.

Moores has been unable to walk for about a decade.

"It took almost 10 horrible years for MS to beat me down from a hickory cane era, where I walked by throwing my left

leg forward and hoping for the best, into this wheelchair," he writes.

He operates his computer with the knuckle of his pinky finger and voice-recognition.

In calling his work *The Stationary Hobo*, Moores explains that he considers himself the most alone person he's ever met.

"Not because I'm a hermit or

unapproachable, I'm just the opposite. It's the tale of the stationary hobo. Even if I did have a fully-tricked-out van, trying to keep it fuelled and maintained would be impossible for financial reasons. Unfortunately, I also have the most dead friends and acquaintances than anyone I know, which makes the social math even worse. So 98 per cent of my meals are taken

alone," he writes.

Moores said he lives \$8,000 or more below the poverty line. It's not unusual for him to choose between paying municipal taxes, buying clothes, having his lawn mowed or having more than one meal a day.

"The maintenance on my home keeps me awake at night even when the MS doesn't," he writes.

Moores' stories detail the battles he's fought over the years with the province's health-care system.

Provincial homecare allows him to continue living in his own home - a home he inherited from his parents. He worries, however, that his homecare could be cut to the point where he'd be placed in an institution.

"Soon after that I perish," he writes.

In his writing, Moores describes himself as a prisoner in his own body.

"All I have to offer now are the stories I can put together and the images that I can construct," he said during the phone interview.

Moores's work - through the power of the written word - should not be underestimated.

While he can no longer walk, he can, and does, place his readers in his shoes. Those who live with a disability will relate to his struggles.

His stories could also help decision-makers more fully understand the struggles faced every day by people living with chronic illnesses and other long-term disabilities. That could be me; it could be you - tomorrow.

Moores's series can be found at www.artesian-paradise.tumblr.com.

danette@nl.rogers.com

Newfoundland & Labrador > News > Local

Clarenville man demands public apology from Eastern Health

CLARENVILLE-A Clarenville man living with Multiple Sclerosis (MS) is demanding a public apology from Eastern Health.

Mark Squibb | Posted: June 5, 2017, midnight | Updated: Sept. 30, 2017, 6:24 a.m. | 4 Min Read

Barry Moores has written a public letter to David Diamond, president and CEO of Eastern Health, demanding a public apology after he says Eastern Health called RCMP officers to his door on Thursday, May 18.

Moores lives alone in his Shoal Harbour home inherited from his parents. His bookshelf is lined with Steinbeck and Hemingway. He likes the music of Charles Mingus, Miles Davis, and John Coltrane. He has loved baseball since he was a boy.

He has worked as a reporter and editor for various papers, taught journalism at Western Community College in Stephenville, worked with CBC radio, and co-founded Natural media in 1994.

Moores, who was diagnosed with MS in 1993, is confined to his home and wheelchair, and is attended to by home-care workers.

His home-care worker was out on an errand on May 18 when RCMP officers knocked on his door, and Moores was unable to answer the door. He says the officers announced that they would be coming in, and proceeded to do so, and that they said they were there on the behest of Eastern Health in regards to a post that Moores had to Facebook the previous day.

"They [the RCMP officers] said that somebody at Eastern Health called because they thought you might hurt yourself," Moores told The Packet.

In that Facebook post, Moores claimed that "the well-paid automatons at Eastern Health" cut back his heating supplement by \$600 for 2017-2018.

"As an organization, you have no shame whatsoever. As I expected this year and as I have been telling the whole world for more than a decade now, your inept behaviour toward me as a citizen and so-called client of your health board is forcing me out of the home left for me by my war veteran father and my mother who was a school teacher in Clarenville for 30 years," Moores' post read.

"You have the option of reversing this right now. Or fighting me into my grave. The second option is a scenario you cannot win," the post concluded.

Moores says for Eastern Health to involve RCMP officers was irresponsible on the part of Eastern Health.

"It's ridiculous, it's ludicrous... I just don't understand why they would do that without contacting me first."

"At the best this is not at all well thought through. At the best inept and incompetent. It's not meeting professional standards, and that's at the best. At

"I'm not criticizing the police... they're in a situation where Eastern Health made them jump," said Moores.

Eastern Health did not comment on the specific incident when contacted by The Packet, but they did provide a statement regarding their policy.

"The safety and security of our patients, clients, residents, visitors, staff and volunteers is a priority for Eastern Health. The nature of providing health-care services across our region sometimes requires staff to visit clients in their homes. It is our responsibility to ensure that these working environments are safe. Eastern Health takes this responsibility very seriously and has an established policy and protocols to manage any perceived threats that are received," the statement read.

"For example, when contacted directly by a member of the public via our social media accounts, phone lines and/or emails with a message that raises potential safety concerns, the process is to consult with relevant programs if it is felt that the safety of staff may be jeopardized. If the review determines a situation may be unsafe, Eastern Health, as outlined in Eastern Health's 'Violence Prevention Response and Support' policy, has legal and regulatory obligations to report violent incidents, including threatening statements and/or behaviours, to varying authorities such as the police and professional regulatory bodies. The authorities may decide to conduct investigations in relation to such incidents, and determine any required action."

Moores, in the open letter, calls the actions of Eastern Health both careless and dangerous, and says that incident humiliated him in his own neighbourhood, and brought about a great deal of stress.

"One doesn't even need to be a publicly-funded self-described health expert to know stress is the first danger to MS," Moores writes.

He says that the act was also one of censorship and an example of journalist intimidation.

